HIV/AIDS ORPHANS AS HEADS OF HOUSEHOLDS:

A CHALLENGE TO PASTORAL CARE

BY

ZAMANI   MAQOKO

Submitted in partial fulfilment of the requirements for the

Degree of

MASTER OF THEOLOGY

In the

Faculty of Theology

Department of Practical Theology

UNIVERSITY OF PRETORIA

SUPERVISORS: PROF. YOLANDA DREYER

PROF. M J MASANGO

2006

ACKNOWLEDGEMENTS

I would like to take this precious moment to express my deepest words of gratitude to people who played a major role in my life and throughout this study. Without their support in various forms, this work would have not been started or completed.

- Firstly my deepest gratitude goes to the heavenly Father whose grace and love has journeyed with me throughout this work.
- I wish to express my deepest gratitude to my family, especially Mlakes my younger brother who's been so concerned about how far am I with my work. His concern encouraged me to work very hard until I finish. Equally, my gratitude goes to my mother who always encouraged me to study and with her prayers.
- My supervisor Prof Yolanda Dreyer, who journeyed with me until the last moment. Her guidance, encouragement and critiques have motivated me to complete this work.
- My heartfelt thanks also goes to Prof M. J Masango for the foundation he has laid for this study. To you Sir I say: *ukwanda kwaliwa ngumthakathi, maz'enethole.*
- My wife Mpolokeng, my son Asive who has endured my late nights and my early mornings. I treasure your support and encouragement.
- To my brother Khusta and my girls Noluvuyo and Andiswa I love you.
- Mrs Peete and Mr Maduna, I thank you. You made this study a success. You opened gates for me. You organised participants for this study. I again say: thank you very much.
- The community of Bophelong where I conducted my fieldwork deserves special mention. You welcomed me into your homes and sometimes compromised you family privacy. But because you wanted to help other people who are in the same situation as you, you opened your gates; you shared some family secrets with me, which I promised to keep. May the Good Lord be with you all and your households.

DEDICATION

I wish to dedicate this work to many young boys and girls who have lost their parents to HIV/AIDS pandemic and have to find themselves without any adult caregivers. Who have to leave school in order to take of their ailing parents and after parent's death they have to be heads of households and fend for themselves. Who have to struggle to make ends meet. May the communities in which they live and the churches they draw their strength to live and their extended families that rejects them find it in them to be in solidarity and empathise with them, instead of judging, discriminating and isolating them

ABSTRACT

HIV/AIDS has done a great damage to families and their children. Due to HIV/AIDS, grandmothers find themselves caring for their sick children, grandchildren and orphaned grandchildren. Because of the large number of AIDS orphans, the existing pool of community-based support has become saturated. Therefore these children now have to fend for themselves. They are forced to become heads of the households and breadwinners. In this situation the older children have to assume the role of looking after their siblings. Death caused by HIV/AIDS leaves children vulnerable, in great distress and poverty. The stigma and discrimination related to the HIV/AIDS pandemic has resulted in the isolation of infected persons and their family members. Sometimes the isolation continues until and even after the children become orphans. It is a fact that HIV/AIDS orphans as heads of households are undergoing traumatic experiences. On the psychological level children are traumatized by the illness of their parent(s).

Because of the high rate of unemployed and pervasive poverty in this country many families are reluctant to take in orphans. Other problems are: the cost of treating illnesses caused by HIV/AIDS places a huge economic burden on families. After death, funeral expenses contribute to the toll exacted by HIV/AIDS. It becomes increasingly impossible for families and communities to absorb the cost and support the large numbers of children alone. Some women hesitate to take in the orphaned children of their relatives because they fear that their husbands will abuse the children

Investigation into the existing literature reveals that previous studies concentrated mostly on the educational, psychosocial and emotional needs of people with HIV/AIDS. Studies on child headed households' deals primarily with children's rights and the accessibility of social grants for children infected and affected by HIV/AIDS. Although not much was available statistically, for the purpose of this study I have identified several households headed by children, whether the cause of this was HIV/AIDS or misfortunes such as

parental suicide or accidents. This study has focused on the experiences of HIV/AIDS orphans in child headed households. This study has also investigated whether HIV/AIDS orphans suffer more deeply psychologically and emotionally than children who have been orphaned by other circumstances other than AIDS.

This study highlights the many difficulties and setbacks experienced by HIV/AIDS orphans who become heads of households after the death of their parents. An exploratory research design was utilised and qualitative approach was followed. Five households were chosen as samples that complied with requirements of this study. Participants in these households were between ages 13 and 18 years old. The information gathered by means of literature and empirical research reveals that the children affected by HIV/AIDS are not only physically impoverished, but also psychologically, socially and spiritually. They suffer from fear, depression, stress, anxiety, stigmatisation and discrimination, isolation, and are often scorned by peers.

HIV/AIDS orphans experience psychological trauma on account of witnessing their parent's illness and death (or departure), carrying the responsibility of caring for sick parents, and after their death, for siblings. The socio-economic circumstances of HIV/AIDS orphans in child headed household often force them to drop out of school, in order to find ways of providing for the family. The traumatic experience of HIV/AIDS orphans and children who have been orphaned to other circumstances, are similar.

The following themes can be considered for future research:

- Stress experienced by HIV/AIDS orphans in child headed households due to HIV/AIDS.
- The role of churches in identifying and supporting orphans in child headed households.

Key Words

HIV/AIDS

ORPHANS

CHILD-HEADED HOUSEHOLDS

WELL-BEING

PSYCHOSOCIAL

PASTORAL CARE

COUNSELING

TRAUMA

STIGMA, DISCRIMINATION

CHILD RIGHTS

COMPASSION

CHILD DEVELOPMENT

LIST OF TABLES **PAGE**

VIII

TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION AND ORIENTATION

CHAPTER 2: DEFINITION OF KEY TERMS

CHAPTER 3: HIV/AIDS AND TRAUMA

CHAPTER 4: PSYCHOSOCIAL FACTORS

CHAPTER 5: FIELD RESEARCH

CHAPTER 1
INTRODUCTION AND ORIENTATION

1.1   Introduction

The aim of the chapter is to provide a background and orientation of the experiences of HIV/AIDS orphans and orphans in child headed households. In 1998 a study by the ministry of health suggested that by 2005 between 197 000 and 250 000 children would be orphaned in kwaZulu Natal alone. These figures are expected to grow if something is not done. HIV/AIDS has done a great damage to families and their children. It has devastated lives of many people and affected individuals, families, and communities (WCC Study Document 1997:1). According to UNICEF (2003b: 9) the AIDS pandemic has reached almost every part of the world. A joint programme between UNAIDS and the United Nations indicates that in 1996 approximately 20 million people around the world were infected by HIV/AIDS. More than 6 million are already dead (World Bank 1999:13).

Statistics (UNAIDS/WHO 2003:3) disclose that by 2002 approximately 40 million people worldwide were living with HIV and 2,5 million were children under the age of 15. Globally, by the same year there were 14 million children who were orphaned by the pandemic. A great number of these children had become the heads of households, were forced to look after themselves, dropped out of school, became vulnerable to many forms of abuse and had to look for work in order to care for their siblings. It is vital to ensure that information about dangers of HIV/AIDS and the steps necessary to tackle this crisis is available to all – policy makers, community and church leaders. These people should collaborate by collecting and disseminating information that will help protect people from the pandemic. One way of preventing the spread of HIV infection is the action taken by UNICEF (2003b: 10) to ensure that young men and women between ages 15 to 24 have access to information, education, and life skills development.

Some of the effects of HIV/AIDS are that people become impoverished, heart-broken and their human rights violated. The results of this are that a great number of people worldwide are falling ill, suffering physically, emotionally and spiritually (WCC Study Document 1997:1). A study by USAID (2004:7) shows that HIV/AIDS is the primary factor, which contributes to the increasing number of orphans in the Sub-Saharan Africa. In 2003 there were approximately 43 million orphans in the Sub-Saharan Africa. According to Sloth-Nielsen (2004:1) approximately 840 000 children in South Africa have lost their mothers, mostly because of HIV/AIDS. By the year 2015 this number is expected to have increased to 3 million. Research among orphans and other vulnerable children and youths shows that recommendations and the ensuing programmes have failed to make key age related distinctions. Physical, cognitive, emotional, psychological differences that characterize children and adolescents in different stages of development have largely been ignored (UNICEF/UNAIDS/USAID 2004:13).

In the past traditional structures such as extended families and communities have played a major role in caring for orphans. Due to HIV/AIDS grandmothers find themselves caring for their sick children, grandchildren and orphaned grandchildren. UNICEF/UNAIDS/USAID (2004:13) emphasizes that, in order to survive and thrive, orphaned children and adolescents need to grow up in a family and community environment that provide for their changing needs. Because of the large number of AIDS orphans, the existing pool of community-based support has become saturated. Therefore these children now have to fend for themselves. They are forced to become heads of households and breadwinners. This begins when parent(s) take ill and cannot perform their parental duties. The older children have to assume the role of looking after their siblings. Deaths caused by HIV/AIDS leave children vulnerable, in great distress and poverty. This is also evidenced by situations of child headed households. I will expand on this later in the chapter.

The behaviour that leads to HIV infection frequently provokes social and moral judgment and the subsequent discrimination against infected and affected people. The powerful stigma and discrimination related to the HIV/AIDS epidemic has resulted in the isolation of infected persons and their family members. Misinformation, ignorance and prejudice about HIV/AIDS limit the willingness of a community to provide for the orphans who are affected by the disease. UNICEF (2003b: 6) formulates it as follows: "[F]rom the beginning the HIV/AIDS epidemic has been accompanied by fear, ignorance and denial leading to silence and inaction by government and to stigma, discrimination and abuse against people with HIV/AIDS and their families." As the number of people infected with HIV/AIDS increases, access to medical care becomes difficult and expensive for everyone, including those not infected. When parents fall ill, particularly in poor families, children come under duress and the effects of this often continue in different ways for the rest of their childhood. They often take on the heavy burden of nursing their ailing parents because family members and relatives are not willing to help.

Child headed households are not new in the South African society. Although there is not much information regarding child headed households, the report of Deborah Ewing (2002:83) confirms that situations do exists where adult siblings of orphans or adolescents who still go to school, often head up households. Child heads of households sometimes have the support of an elderly person from the neighbourhood, but other children care for sick parents without any adult support. HIV/AIDS orphans in child headed households in the South African context are likely to be poorer and less healthy than children who are not orphans. In addition UNICEF (2003b:26) state that AIDS orphans are likely to suffer damage to their cognitive and emotional development, have less access to education and are subjected to the worst forms of child labour.

1.2   Problem Statement

The situation described above is indicative of the fact that HIV/AIDS orphans as heads of households are undergoing traumatic experiences. Some such experiences threaten their lives. On a psychological level children are traumatized by the illness of their parent(s). This is exacerbated by the stigma and discrimination attached to HIV/AIDS. In addition UNICEF (2003a:2) lists some other experiences these children have:

- **Economic hardships**. With parents unable to work and savings spent on care, children are forced to take on the adult role of supporting the family.

- **Having to leave school**. The pressures of having to care for parents and siblings while trying to earn an income can cause children to drop out of school, even while their parents are still alive. The pressure to abandon schooling intensifies when one or both parents die.

- **Malnutrition and illness**. Orphans and other affected children are more likely to be malnourished or to fall ill. They are also less likely to receive the medical attention and healthcare they need. Poverty is the root cause of this vulnerability, but often neglect and discrimination by adults in whose care they have been left, are also contributing factors.

- **Loss of inheritance**. When parents die, orphans are often cheated out of property and money that are rightfully theirs.

- **Fear and isolation**. Dispossessed orphans are often forced out of their homes to unfamiliar and even hostile places, be they camps for the displaced or the streets.

- **Increased abuse and risk of HIV.** Impoverished and without parents to educate and protect them, orphans and other affected children face every kind of abuse and risk, including becoming infected with HIV themselves.

4

> Many are forced into exploitative and dangerous work, including exchanging sex for money, food, protection or shelter.

My research will add to the list of experiences encountered by HIV/AIDS orphans. Those traumatic experiences will be reported in chapter 5 of this study.

The question, which presents itself, is why South Africa has so many child headed households? What has happened to "ubuntu" (humaneness), which Africans used to have? This study will examine the factors that cause HIV/AIDS orphans to head households. The investigation begins with HIV/AIDS itself.

HIV/AIDS was identified in 1981 and has since then taken on epidemic proportions. It is primarily a sexually transmitted disease. Issues raised by the pandemic touch on cultural norms and practices, socio-economic conditions, gender, economic development, human responsibility, sexuality and morality (WCC Study Document 2000). The problem does not start when the children are orphaned by HIV/AIDS. It starts much earlier when family members; relatives, community members and church members hear that someone has been infected. Then they isolate that home, which obviously also affects the children. Sometimes the isolation continues until and even after the children become orphans. Prior to the AIDS epidemic, orphans were a common phenomenon. However, in the past satisfactory solutions were found by society for the majority of the children. The difference now is that there is a great increase in the number of orphans because of HIV/AIDS (Ng'weshume et al 1997:347). This increase has impacted severely on the extended families that used to take care of orphans on a voluntary basis. Africans saw this as a sign of "ubuntu". However, this has changed totally. African "ubuntu" has failed AIDS orphans. Uncles and aunts no longer take care of orphans.

Because of the high rate of unemployment and the pervasive poverty in this country many families are reluctant to take in orphans. However, the even greater problem is the fear that the HIV/AIDS epidemic has created among people. The fearful stigmatise and discriminate against those infected and

affected by HIV/AIDS. Families and communities discriminate against rather than help HIV infected and affected people and their households. Hence Pharoah (2004:94) notes that the epidemic makes its impact felt on all levels of society. He states that HIV/AIDS is creating and exacerbating not only physical poverty, but also emotional, psychological and social poverty in the lives of HIV/AIDS affected children.

Hepburn (2002:89) purports that poverty is the primary barrier to caring for orphans locally and nationally. She adds that without adequate resources to feed, clothe, and counsel these children, their basic needs go unmet. If, indeed, poverty is the primary problem, then communities should explore ways of balancing the costs and alleviating poverty, while government provides foster grants and child support grants. However, fostering is not necessarily the best solution. Some fostered orphans are not benefiting from the grants, as they should, because those who are supposed to care for them use the money for themselves. The irrational fear of becoming infected through social contact or through caring for the sick, also leads to ostracism and isolation of the infected person by family members or the surrounding community (Ng'weshume et al 1997:309). For all of these reasons, therefore, many orphaned children are in the position of heading households.

The cost of treating illnesses caused by HIV/AIDS places a huge economic burden on families. According to UNICEF (2003:17) studies done in Côrte d' Ivoire shows that when a family member has HIV/AIDS, the household spends four times as much on healthcare as an unaffected household. Even after death, funeral expenses contribute to the toll exacted by HIV/AIDS. Given the extent of the HIV/AIDS epidemic it has become increasingly impossible for families and communities to absorb the cost and support the large numbers of children alone.

Some women hesitate to take in the orphaned children of their own relatives because they fear that their husbands will abuse the children. On account of the taboo of incest, which inhibits the sexual abuse of one's own family, it would be

6

safer for the children if the men should take in the children from their side of the family. A study conducted among HIV infected mothers in Kenya indicates that many mothers are concerned about the future of their children. Only 10% were concerned about their emotional well-being. Their concern was mostly for the children's physical safety and care.

In the light of the above, the investigation into the situation of HIV/AIDS orphans who find themselves heading households, focuses on the following main questions:

- What is the relationship between extended families and HIV/AIDS orphans in child headed households?

- What are the experiences of the HIV/AIDS orphans as heads of the households?

- How do AIDS orphans see their future? Do they have plans for the future?

The study will conclude with suggestions and recommendations for mitigating the impact of HIV/AIDS as experienced by HIV/AIDS orphans who have become the heads of households.

1.3   Literature Review

Investigation of the existing literature reveals that previous studies concentrated mostly on the educational, psychosocial and emotional needs of people with HIV/AIDS (Hepburn 2002:87-98; Foster 2002:502-504; Mengel 2003; Chabilall 2004). Studies of child headed households deal primarily with children's rights and the accessibility of social grants for children infected and affected by HIV/AIDS, child headed households and other vulnerable children (Rosa & Lehnert 2003; Sloth-Nielsen 2004; Rosa 2004). Because of an increasing number of children who have lost both parents to AIDS, the number of child headed households is also growing. Although not much was available statistically, for the purposes of this study I have identified several households

headed by children, whether the cause of this was AIDS or misfortunes such as parental suicide or accidents. I have also investigated the socio-economic impact of HIV/AIDS on children. This includes concerns such as malnutrition, reduced access to education, health care and child labour. Books (1998:48) states that research has shown HIV affected children and youth to be a population at high risk. They are prone to developmental, behavioural and mental health problems, teenage pregnancy and becoming infected by HIV themselves. In this study the experiences of HIV/AIDS orphans as heads of households will therefore be investigated on psychological, emotional and spiritual levels.

1.4   Aims and objectives of the study

Some HIV/AIDS orphans find themselves in the stressful situation of heading up a household. Often they have to care for their siblings. In some households HIV also infects younger siblings. The contribution of this study is that it focuses specifically on the experiences of such orphans in child headed households. The study will also investigate whether HIV/AIDS orphans suffer more deeply psychologically and emotionally than children who have been orphaned due to circumstances other than AIDS. The objectives of this study are the following:

- ➢ To listen to the experiences of some HIV/AIDS orphans who find themselves in the position of heads of households.
- ➢ To establish whether there are differences between the experiences of HIV/AIDS orphans and those of children who have been orphaned on account of circumstances other than HIV/AIDS.
- ➢ To investigate how the progress of these children through the stages of child development is affected due to the loss of their parents and the ensuing circumstances.
- ➢ To provide suggestions for mitigating the impact of HIV/AIDS as experienced by orphans as heads of households.
- ➢ To determine what role churches can play to support HIV/AIDS orphans heading households in the absence of family.

> ➤ To investigate the role of Non-governmental Organizations (NGO's) in providing help for HIV/AIDS orphans in child headed households.

> ➤ To examine what support (financially, socially, educationally, emotionally, spiritually) can be offered to HIV/AIDS orphans as heads of households by other organization such as schools, the community and government.

1.5 Significance of the study

Both in the Old and New Testaments, the community of believers is asked to care for orphans and widows. This shows that God cares for people. Douglas et al (1982:836) use the term "fatherless" to denote orphans. For the purpose of this study I will add "motherless". This exploratory study strives to assist pastors, clergy, and other caregivers to develop a pastoral and caregiving focus on the plight of AIDS orphans. In a patriarchal social system such as that in which the Bible originated, men were regarded as the heads of households. These days, however, women are also found in the workplace and things have changed. Some women have even become breadwinners and/or heads of households. The HIV/AIDS pandemic has caused a new social situation, namely that young boys and girls of necessity have become the heads of households. After the death of their parents these children are often left without primary caregivers when no members of the family are available to take care of them. They then keep the family going themselves and become responsible not only for themselves but also for younger siblings.

HIV/AIDS orphans not only face the horror of losing their parents or families to HIV/AIDS epidemic, but also experience the void of being rejected, isolated, stigmatised and discriminated against by family, friends, the community and church members. Some such children become suicidal because they feel that life has no meaning for them. Children in child headed households, who are still in the process of becoming adult, are suddenly faced with very real practical problems such as raising their younger siblings, and trying to survive. Foster (2002:503) warns that postponing efforts to address HIV/AIDS orphans'

psychosocial needs will lead to long term emotional and behavioural disturbances. Forster continues to say that older people frequently overlook these needs because they have difficulty recognizing the psychological reactions. It is a fact that individuals react in different ways. For example, after having heard the news about the death of a loved-one, children may be happily continue to play with other children. This denial does not mean that the children do not care, but they are protecting themselves against overwhelming painful feelings. Although they do not show reaction to death, this does not mean they are not grieving. Children have fears when faced with the death of a significant person. For them one of the most frightening experiences is to be separated from parents and left unprotected. Parents provide them with a sense of security in the world.

Granot (2005:7) states that when children suffer, adults want to wrap them in their arms and protect them. This reminds me the spirit of "ubuntu" (humanness), which brings me to the African context of caring for humanity. The loss of parent(s) through death is painful and devastating. Children can experience the loss of a parent or parents on account of a variety of circumstances. The most traumatic of all is the death of parent from disease, accidents, suicide and murder. Kubler–Ross (1991:10) has commented that dying is a human process, but death remains a mystery to us all. Although people encounter death every day, they never become familiar with it.

The loss of parent(s) can be the result of divorce or when a parent ceases to function as such as in the case of addiction to alcohol or drugs. This is like death for the children. Granot (2005:7) calls this loss "an emotional debilitating condition, emotional rejection or abandonment". When children have to assume the takes of acting as parents and look after siblings, it is painful and traumatic for them because they have to perform duties for which they are not been prepared. Horowitz (Moutona 2001:191) describes this role as follows: "[P]arenting is composed of tasks, roles, rules, communication, resources, and relationships." HIV/AIDS orphans in child headed households certainly lack these

10

parenting skills. Parenting is not about being in a particular family structure. Rather it refers to a process of guiding children from conception and birth through development challenges until adulthood. HIV/AIDS orphans will miss this guidance through the stages of development on account of the absence of their parents of adult caregivers. They are the ones who then have to provide this guidance for their siblings. This is an impossible situation. There is no way in which these children can provide adequate parenting to others. This study highlights the many difficulties and setbacks experienced by HIV/AIDS orphans who become heads of households after the death of their parents.

The study focuses on the psychological, emotional and spiritual welfare of HIV/AIDS orphans as heads of households. It also explores how and why HIV/AIDS orphans are subjected to heavy workloads, abandon school and decide to look for jobs, and/or pursue life on the streets. This study will also examine traumatic experiences of HIV/AIDS orphans in child headed households, and how they cope with the resultant stigma and discrimination, death, distress, parental illnesses, rejection and isolation.

1.6   Research Methodology

Pennington (1986:39) points out that, since the inception of psychology as an empirical discipline, psychologists have acknowledged that childhood, especially the early years, is an important foundation for the functioning of the person later in adolescence and adulthood. He distinguishes between the older view of children as "small adults" and the present idea that children operate at qualitatively different intellectual, emotional and social levels than adults.

Because of the importance of childhood for the later lives of people on the one hand and the problematic childhood of AIDS orphans, I have chosen to investigate their lives and experiences by means of the theories of child development psychology. I will depart from the developmental model of Erik Erikson (1963) and will then make extensive use of the work of developmental

psychologists who used and expanded Erikson's theory. In his model Erikson (1963:222-241) introduces eight stages of human development, from infancy to adulthood. At each stage the individual has to negotiate a particular "crisis". Though Erikson is indebted to Freud's model of the oral, anal, phallic and genital phases, his emphasis is social rather than biological. Over against the determinism found by Freud Erikson is of the opinion that basic life choices influence but do not determine the way in which people come to terms with the crisis of each stage (see Smelser 1981:32). Boeree (1997:4) discusses the differences between Freud and Erikson. He argues that Freud emphasized the influence of the parents on the child's development, whereas Erikson saw the relationship as more mutual: children also influence their parents' development. These interrelationships between parent and child have great meaning in the subsequent life of a child, especially when the parents had mature abilities and social support. The benefit of this is absent from the lives of the many Sub-Saharan African children who often not only have parents due to AIDS, but have the added pressure of have to become the heads of households and care for siblings. Already when the parents became ill, the children had to care for parents and siblings. This extreme pressure on young children has resulted in adolescents leaving school in order to care for their siblings. As far as their development is concerned they lack both the guidance and influence of parents and the education, which could be had from schooling. The foundations on which to build their lives are severely damaged if not totally non-existent.

This study focuses on the stages from early childhood to adolescence. In an African context these stages are critical for building the pivotal African value of "ubuntu", which is also emphasized in African rituals.

According to Erikson early childhood is from age 2 to 6 and the crisis at this stage is that of initiative versus guilt. Boeree (1997:7), building on Erikson, views "initiative as a positive response to the world's challenge, taking on responsibilities, learning new skills, and feeling purposeful. Granot (2005:64)

12

differs from Erikson and Boeree in pinpointing early childhood as from birth to three (3) years. Although Granot does not mention the reason for this view, I can relate to his idea from an African perspective. In some African communities a ceremony is conducted between the ages of 1 and 3 to introduce the new member of the family to the ancestors. A goat or a sheep is sacrificed. This ceremony contributes to strengthening the young child's sense of him- or herself as a unique individual. Young children like to draw the attention of adults by asking many questions. They also attempt to discover how things work and by building or inventing novel devices. By doing this they are imaging the future that is not yet reality. Hence initiative is an attempt to make that non-reality a reality (Boeree 1997:7).

At this stage (early childhood) sex and other role definitions such as social class for example, begins to shape. Failure to develop a sense of purpose results in lack of independence and a persistent sense of guilt over this failure (Pennington 1986:39). This stage is also called "genital-locomotor stage" or play age. This is a period where parents have the responsibility of encouraging and appreciating the child when he/she is doing the right thing. When parents die at this stage, there is a good chance that the development of the child will slow down or that the child will regress to an earlier stage of development. When the child regresses, motor development and motor independence, including crawling, walking, talking and feeding him/herself, are affected.

According to Newman and Newman (1999:36) the crisis at the stage of adolescence is identity/intimacy versus role confusion. Adolescence begins with puberty and ends around 18 to 20 years. At this stage key developmental experiences include physical and sexual maturation, progress toward social and economic independence, and further development of identity. The task during this stage is to achieve ego identity and avoid role confusion. Boeree (1997:8) describes ego identity as "knowing who you are and how you fit into the rest of society". When an adolescent is confronted by role confusion, Boeree (1997:9)

13

calls this an "identity crisis". This stage is marked by rapid changes. Sometimes these changes will make adolescents feel like adults though they are not really ready to assume the tasks of adults, for example being a parent. Signs of anxiety and distress can be identified at this stage hence suicide is not uncommon among adolescents. At this stage they search for their "true self". The attempt to answer the question "who am I?" occupies teenagers (Pennington 1986:41). At the loss of their parent(s) or family members through death they may feel resentment and anger. They could seem coping but are in fact experiencing depression, hopelessness, and an increased feeling of vulnerability. According to UNAIDS (2004:17) this can lead to a sense of alienation, desperation, risk taking behaviour and withdrawal. If parents die at this stage and adolescents have to take the responsibility for siblings, is could most certainly be traumatic to them. If they do not have good adult role models and open lines of communication with mature persons such as member of the extended family the situation is even worse. While other young people are involved in dating and relationships, HIV/AIDS orphans as heads of households have to take up adult responsibilities such as looking after siblings and assuming parenting roles.

Erikson's theory is based on western culture and therefore I will have to supplement his insights on adolescence with information from an African social context. In African cultures rituals are performed and young people have to prove that they have certain accomplishments before they are recognised by the community and ancestors. These rituals distinguish adults from children. In some cultures boys and girls undergo circumcision before which they are taken to a secluded area and isolated for a certain time. During this period they are taught many things, including how to raise a family. This education equips them mentally, bodily, emotionally and morally for adulthood. The cutting of flesh is symbolic of shedding childhood and getting ready for adulthood (Mbiti 1991:98-99). Once a person has gone through initiation he or she is no longer an outsider. Initiated young people enjoy full privileges and also shoulder some responsibilities in their immediate family and in the community. After initiation a

person may perform religious rituals, can get married and can have children. This stage can be extremely difficult for AIDS orphans since there is no way for them to manage the expenses of initiation. Also there is no one to provide them with direction and support. An AIDS orphan who cannot participate in initiation for these reasons, will have to watch others of their age go out, knowing that when they return he or she will be an outsider to them. Their language and experience will be different now. Those who have not been to initiation school have to show respect for those initiated. In addition to the financial worries and burdens AIDS orphans already have, not being able to participate in important cultural *rite de passage* will further affect them on an emotional and social level. It will lead to alienation and social marginalisation.

Traumatic experiences of HIV/AIDS orphans on a psychological, emotional, and spiritual level will be discussed in chapter 4 which will focus especially on psychosocial factors. Some HIV/AIDS orphans may not reach Erikson's last stages of human development, because of the impact of AIDS in their lives, households and future.

This study has implemented the qualitative approach to research because this type of research tends to be open to using a range of evidence and discovering new knowledge. One of the distinguishing characteristics of qualitative research is the fact that the researcher tries to understand people in their own world. Neuman (1997:328-329) states that qualitative research involves documenting real events, recording what people say (with words, gestures and tone), observing specific behaviours, studying written documents or examining visual images. Qualitative research largely relies on the interpretative and critical approaches to social science. The specific focus of this study is to reveal the complexities, challenges, and traumatic experiences of HIV/AIDS orphans who function as heads of households.

1.6.1 Research design

Terre Blanche & Durrheim (1999:28) define research design as "a strategic framework for action that serves as a bridge between research question and execution or implementation of the research". This means that research design enables the researcher to reach his/her goals and objectives. It also includes the manner in which the research is set up, and explaining methods of data collection utilized. The research design utilized in this research is that of exploratory research. The goals (Neuman 1997:20) of exploratory research are the following:

➢ to become familiar with the basic facts, people and concerns involved;
➢ to develop a well grounded mental picture of what is occurring;
➢ to create many ideas and develop tentative theories and conjectures;
➢ to determine the feasibility of doing additional research;
➢ to formulate questions and refine issues for more systematic inquiry;
➢ to develop techniques and a sense of direction for future research.

The aim of this study is to develop an understanding of what HIV/AIDS orphans as heads of households experience in their particular context and situations. I have taken note of Rubin & Rubin's (1995:41) caution that the qualitative researcher has to have a high tolerance for uncertainty, especially at the beginning of the project. It was indeed so that I as researcher I had to be open to the stories of the children and learn from them. Therefore it was not possible to plan the entire design for this qualitative project in advance. According to Rubin & Rubin (1995:41) it is first necessary to familiarize oneself with the topic and general ideas and focus the research and then decide what can be explored later in the research process.

In qualitative research, the researcher may use case studies in order to gather a large amount of information whereas a quantitative researcher looks for patterns in the variables in many cases. Thus, Neuman (1997:331) states that a case study researcher faces an overwhelming amount of data but has been immersed

16

in it. He continues that "immersion gives the researcher an intimate familiarity with people's lives and culture". The researcher looks for patterns in the lives, actions, and words of people in context of the case as a whole.

1.6.2 Research Process

A qualitative research style is organized around theorizing, collecting, and analysing qualitative data. Qualitative data involves documenting real events; recording what people say (with words, gestures, and tone), observing specific behaviours, studying written documents or examining visual images. According to Neuman (1997:328) qualitative data is empirical. Therefore data collection for this study was done by means of observation and interviews.

The study describes and interprets people's feelings and experiences in human terms rather than through quantification and measurement. The interpretive approach tries to harness and extend the power of ordinary language and expression development over years to help us better understand the social world we live in. The interpretive research also tries to describe what it sees in rich detail and presents its "findings" in engaging language.

 According to Terre Blanche & Durrheim (1999:123), qualitative researchers assume that people's subjective experiences are real and should be taken seriously. The researcher can understand the others' experiences by interacting with them and listening to their stories. This study makes use of interpretive research. It relies on first hand accounts, describes what it sees in rich detail and presents its findings. Hence empirical research was undertaken in order to discover what the experiences are of HIV/AIDS orphans as heads of households. The objective of this interpretive research was to make sense of feelings, experiences, social situations or phenomena as they occur in the real lives of these children.

17

1.6.2.1   Selecting the Site

Preceding investigations discovered a suitable area for sampling at Bophelong in the Eastern part of Vanderbijlpark. Many child headed households were found in the Bophelong area. Presently there are about sixty-two (62) orphans living without extended families or other adult caregivers and thirty-seven (37) households headed by children between 13 and 22 years old. Thapelo Maduna a member of Community Based Care (CBC) and Home Based Care (HBC) arrange for me to meeting the group. These two organisations also assisted me in finding HIV/AIDS orphans who function as heads of households, for this study. All the orphans who were interviewed were still at school and had lost one or both parents to HIV/AIDS epidemic.

1.6.2.2   Negotiating access

According to Terre Blanche & Durrheim (1999:136) in order to enter in the process of observing, one should make use of sponsor or gatekeepers. They explain that a sponsor is "somebody who is accepted in the group or culture one wants to study and who helps one to gain initial acceptance. Gatekeepers are people who have a say over who is let in and who is not." In this case the Community Based Care administrator in the Bophelong area was approached with the request to facilitate my research on HIV/AIDS orphans as heads of households. Permission was granted and Thapelo Maduna, who assisted these children with their basic requirements, was asked to make arrangements for me to meet with the participants. After Thapelo had made the necessary arrangements, I visited the children. My first goal was to try and create some form of a rapport and trust. This is necessary in order for the children to be open to share their experiences with me. Trust according to Neuman (1997:355) is not gained once and for all. Instead it is a process, which is developed and built up over time through social nuances, such as for example, sharing personal experiences, story telling, gestures, hints, and facial expression. Rapport also helps create understanding and ultimately the development of empathy.

1.6.2.3   Sampling

Neuman (1997:201) describes sampling as a process of systematically selecting cases for inclusion in exploratory research. The sampling involves a strategy of choosing small groups. The chosen households conform to the requirements of the sampling since they consist of HIV/AIDS orphans as heads of households who are affected psychologically, emotionally, socially, economically, educationally and spiritually as a result of the HIV/AIDS epidemic.

1.6.2.4   The Participants

The population of respondents in this study is young boys and girls who are heads of the households in the geographical area of Bophelong in the Vaal Triangle. This area was chosen because of the presence there of organized structures such as Home Based Care and Community Based Care. The participants selected were almost in school and aged between 13 and 18. Adolescents from five different households were chosen. The first three were heads of households orphaned by HIV/AIDS.

- Household 1: A seventeen year old
- Household 2: An eighteen year old
- Household 3: A sixteen year old

The following were orphaned by circumstances other than HIV/AIDS

- Household 4: A thirteen year old
- Household 5: A fifteen year old

The field research was carried out with the help of Home and Community Based Care organisations in Bophelong. Field research means interacting and becoming directly involved with a certain group of people in order to get inside their world or perspective. It is not easy to enter into other people's world. I require a relationship of trust. In order to use a consistent terminology the study

will call the people studied in the field research "participants". Neuman (1997:348) is of the opinion that field research can be fun and exciting but it can also disrupt one's personal life, physical security, or mental well-being. In field research the idea is that researchers observe as an ongoing process without upsetting, disrupting or imposing an outside point of view.

1.6.3 Data Collection Strategies

Data was collected while field research was in process. The HIV/AIDS orphans as heads of the households selected for this study were observed and interviewed at their homes. The purpose of this was to discover what their and their siblings' real experiences were. The researcher endeavoured to become part of their world as much as possible.

1.6.3.1 Qualitative Interviewing

The first technique of data collecting used in this study was interviews. This was the direct way of obtaining information. Since the study was conducted with exploratory research in mind, semi-structured interviews were used. Semi-structured interviews are structured in the sense that a list of pertinent issues for investigation is drawn up prior to the interview. Denzin & Lincoln (2000:649) state that the list contains some precise questions and their alternates or sub-questions depending on the answer to the main question. They continued by stating that semi-structured interviews help to clarify concepts and problems. They help to establish a list of possible answers or solutions, which in turn, facilitate the construction of more highly, structured interviews. This research wished to ascertain how HIV/AIDS orphans as heads of households adapted, what events meant to them, how they viewed what had happened to them and around them.

This study also identified the complexities in the lives of HIV/AIDS orphans as heads of households as compared to the situations of children orphaned by other

circumstances such as accidents, murder and the like. The interviews were open-ended. Participants were asked the same questions.

Kvale (1996:17) states that the conceptual understanding of the interview that is developed will serve as a framework for classifying methodological and theoretical issues, which arise during the different stages of interview investigation. The model of qualitative interviewing accentuates the relativity of culture, the active participation of the interviewer, and the importance of giving the interviewee the assurance of confidentiality. The interviewer changed the names of the respondents in order to protect their identity. During the interviews the researcher attempted to create rapport with the participants by showing himself to be trustworthiness and accepting of them. I agree with the feminist insights (Reinharz 1992:20) that interviews should not become power games, which only benefit the researcher who in effect "use" the interviewee for their own purposes. Instead, the interviews should actually leave the interviewee better off for having talked to the interviewer. The core concern of the feminists is for maintaining an ethical relationship with those being studied.

1.6.3.2   Observation

Observation was another technique of collecting data for this study. The researcher used the "participant observation" approach because it allowed him to become fully involved in the lives of HIV/AIDS orphans who are heads of households. In this sense the real purpose of the presence of the observer, namely the research project fades into the background while he or she becomes a participant in the lives of the interviewees. Becoming an insider or a participant allows a deeper insight into the research problem. The observer took time to observe children in the early phases of childhood who live in child headed households. Observing and listening are effective ways of gaining information about the children while they tell their stories and identify troubling issues. By doing this, the observer communicates to the child that he or she is really paying attention, values the information they are giving and deeply respect their view of

21

the world. Observing a child's behaviour during the session also gives clues as to the underlying emotional states. It is useful to observe whether or not a child's play is age-appropriately creative or stereotypic, repetitive, and limited, for example, if a child would repeatedly pour sand in and out of container in the tray and do little else (Geldard et al 2002:91). Children aged 3 to 5 are highly imaginative and creative and this should be reflected in how they play.

1.7   Research Programme

Chapter 1: Orientation and Background.
This chapter serves as an orientation and the general introduction for this study. It also outlines the effect of the HIV/AIDS epidemic on humanity and households both locally and internationally. This specific focus is on the experiences (psychological, emotional and spiritual) of HIV/AIDS orphans who function as heads of households.

Chapter 2: Explanation of Key Terms
This chapter provides an explanation of the key terms used in this study. The key terms also contribute to background information.

Chapter 3: HIV/AIDS Orphans and Trauma
This chapter describes the experiences and challenges faced by HIV/AIDS orphans. It explains that they are traumatic to these children. The detrimental effect of the stigma attached to HIV/AIDS is highlighted an exposed as going against the basic human rights human rights of these children.

Chapter 4: Psychosocial Factors
In this chapter the effect of HIV/AIDS on children infected and affected is described and explained by means of the child development model of Erik Erikson and others who expanded on his work. Specific attention is given to the psychological and social factors involved.

Chapter 5: Changes in Family Structure

This chapter discusses the findings of the empirical research conducted among child headed households orphaned by HIV/AIDS. The study will also outline changes in the household and family structures.

Chapter 6: Challenges to Pastoral Care

This chapter describes the challenges to pastoral care to children affected by HIV/AIDS who are left without a primary caregiver. It also discusses the role of structures such as HBC, CBC, and government, which can provide support and assistance.

Chapter 7: Finding and Recommendations

This chapter brings the discussion into conclusion. Findings are presented, recommendations made and directions for further research indicated.

CHAPTER 2
EXPLANATION OF KEY TERMS

2.1   Introduction

This chapter deals with the key terms used in the study in order to orient the reader to some medical terms and key concepts pertinent to this specific research project. Relevant medical terms are HIV and AIDS. Social concepts, which also have theological significance, are "orphans" and "head of household". Since this is a practical theological study the concept "pastoral care" as understood and implemented by the author will also be discussed.

2.2   Human Immunodeficiency Virus (HIV)

Human Immunodeficiency Virus (HIV) is a virus that leads to AIDS. AIDS was first identified in the summer of 1981 in the United States of America. In 1982 it was discovered in some African countries. Between 1983 and 1986 it became clear that the disease was associated a virus which causes a deficiency of the immune system (WCC Study Document 1977:7; Van Dyk 2001:5). According to the Center for Policy Studies (2001) the pandemic was associated with a skin malignancy called "Kaposis Sarcoma". HIV has since spread all over the world and in some countries it is regarded as the number one killer. Many countries are trying to find a cure for the pandemic but so far all attempts have failed. Preventative measures such as the distribution of condoms, have also been implemented. Churches are calling for abstinence. The South African government has combined forces with the churches in order to combine their resources for the fight against HIV and to try and save the nation.

When the HIV virus enters the person's bloodstream it multiplies. The virus attacks the subset of white blood cells and damages the immune system cells. Because the disease is primarily spread by means of sexual contact and sex is a taboo subject in some African communities, the disease has been stigmatised.

The person infected and those affected by HIV/AIDS are stigmatised, rejected, and also discriminated against. This goes against the basic human rights of such people. Discrimination is also against the law. Many people are dying and some leave their children without an adult caregiver to take over the responsibility after their death.

A person who has the virus is said to be "HIV positive", which means that the blood of that particular person contains HIV antibodies. The presence of these antibodies indicates that the HIV virus has infected that person. A person whose blood does not contain HIV antibodies is said to be "HIV negative". The HIV virus attacks and destroys certain kinds of white blood cells that are called CD4 cells or T4 cells. The importance of these cells is that they keep the body in a healthy state at all times. If the body is infected with HIV cells, germs that enter the body are not destroying. Instead they multiply. Hence people with HIV/AIDS contract diseases like "Pneumocystis carinii pneumonia" (Houle 2003:20).

There are different modes of transmitting HIV from one person to another. These modes are as follows: sexual intercourse, re-use of contaminated syringes by injecting drug users, HIV transmission from mother to child through pregnancy, birth, breastfeeding, re-use of needles in medical settings, and transfusion of contaminated blood. One of the reasons that the AIDS epidemic has spread so quickly is that the HIV virus is not easily detected without a blood test. The HIV virus may lie undetected for months after infection has taken place. This period is known as a "window period". Because of the window period people need to be tested more than once after having risked infection. The HIV test does not actually detect the virus itself. Instead it shows whether there are HIV antibodies in the blood. An HIV test also does not determine whether a person has AIDS or will develop AIDS in future. A person is HIV positive only if the HIV antibodies are detected in his/her blood. Houle (2003:83) states that children born to HIV

25

positive mothers usually carry their mother's antibodies in their blood for the first six months to eighteen months.

2.3 Acquired Immunodeficiency Syndrome (AIDS)

The HIV virus can lead to AIDS. Acquired immunodeficiency syndrome (AIDS) is a disease that causes the failure of the immune system. Houle (2003:7-8) explains that the word "acquired" means that it is a disease caught from someone else. It is transmitted from person to person and is therefore contagious. "Immunodeficiency" means that there is a deficiency, a defect or a problem with the body's immune system, which prevents illness and aids the healing process. "Syndrome" can be defined as a group of symptoms that together indicate a certain problem. Although there are some differences as to whether HIV causes AIDS or not, Houle (2003:8) is of the opinion that the virus called HIV, or human immunodeficiency virus causes AIDS. There is no explicit proof; as yet that HIV does not cause AIDS.

A person has AIDS when his/her immune system has been damaged so severely by HIV that it can no longer ward off infections. As the disease progresses, people with HIV/AIDS fall victim to opportunistic infections, which their bodies would normally have been able to fight off. These opportunistic diseases (severe diarrhoea, or the rapid loss of weight; anaemia; Kaposi's sarcoma; pneumocystis carinii pneumonia; thrush or oral candidiasis, a fungal infection in the mucous membranes of the mouth; herpes; shingles; tuberculosis; and damage to the nervous system that may affect a person's memory or cause dementia) then become the cause of death.

HIV/AIDS is now acknowledged as the most important health challenge in South Africa (Centre for Policy Studies 2001). Sonja Giese (in Gow & Desmond 2002:59) examined the impact of HIV/AIDS epidemic on the health of children in South Africa. She states that the AIDS epidemic is expected to have a severe effect on child health indicators, morbidity and the mortality of women and young

adults, as well as on the number of children who will be orphaned. Many or these orphans will be left without caregivers and breadwinners, which will cause children to live in conditions of poverty and neglect.

2.4   Orphans

An orphan is described as a child who lost one or both parents. UNAIDS (2002) estimate that 660 000 children in South Africa have become orphans due to HIV/AIDS. They define an AIDS orphan as a child, aged between 0 and 14 years of age who has lost one or both parents to AIDS. According to Hepburn (2002:88) "orphan" is a socially constructed concept the meaning and content of which varies among cultures and countries. For example, in some cultures it refers to children who have lost one parent, while in other cultures the term is reserved for children who have lost both parents. Lindblade et al (2003) describe an orphan as a child who has lost either or both parents and further refine the categories as maternal, paternal, and double (both parents deceased). Maternal orphans are children whose mother has passed died but whose father is alive. Similarly paternal orphans are those whose father is dead but the mother is alive.

Douglas et al (1982:863) describes an orphan as "fatherless", the term, which is also mentioned in King James Version of the Bible (Dt 24:17). In the patriarchal cultures of the Bible any person without the protection of a patriarch (father) was in dire straits – this goes for orphaned children as well as widows (see Van Aarde 2001). Today one would add "motherless" to the predicament of orphans, since in contemporary cultures a woman on her own can quite adequately take care of children. However, even in the Ancient Near Eastern culture of the Bible the Covenant codes (Ex 22:21-22; 23:9-11) demand humanitarian attention to all who are needy and also forbid unjust acts to any needy person. The needy included three universal groups: the poor, the widows and orphans. The Covenant codes and the Deuteronomic code particularly were most solicitous for the welfare of poor, orphans and widows (see Dt 16:11,14), protecting their rights

of inheritance and enabling them to share in the great annual feasts and to have a portion of the tithe crops (Dt 26:12).

The Code of Hammurabi shares the same sentiments as Covenant Code concerning needy people. This code also uses the three-part expression, the poor, the widow and orphans. Deuteronomy 10:18 speak of God's compassion for the needy as followings: "God work on their behalf". Of injustice toward the needy it is said that "… condemnation awaits those who oppress them" (Dt 27:19; Ml 3:5). Nardoni (2004:82) explains that doing justice means restoring people to their rightful social condition so that they become active and free members of society again. Justice is based on the will of Yahweh. Yahweh does not want people who live in the territory of community to suffer for want of necessities. God commanded the Israelite community to act responsibly towards the needy. Other texts which also refer to justice towards orphans, are the following: Job 24:3,9; Psalm 10:18; 68:5; 146:9; Isaiah 1:23; Jeremiah 5:28-29 and Hosea 14:3. The New Testament injunction is similar: "… care for the orphans and widows in their distress …" (Ja 1: 27, NRSV). This verse shows that God is much concerned about the welfare of orphans. The faith community as a healing community should follow this example. So far, however, churches have not done much to care for orphans and child headed households. Non-governmental organizations (NGO's) are the ones who are doing the work with HIV/AIDS orphans and child headed households.

There are different reasons for children becoming orphans. Sloth-Nielsen (2004) mentions for instance that children are orphaned or left without adult caregivers on account of fatal car accidents. Parents migrate or otherwise abandon their children. Some parents were snatched and others killed by the apartheid system during the struggle for liberation. For all of these young children have been left orphaned and vulnerable. Some parents are killed and children left homeless on account of disputes and wars, for example, the disputes in KwaZulu Natal and

28

the civil war between the Qumbu and the Tsolo. Riots during the old apartheid system and black on black violence have also taken their toll.

HIV/AIDS has now joined the ranks of these causes for children to become orphaned. The increasing effects of the disease jeopardize the rights and well-being of these children. The responsibility of caring for orphans has become a major problem in this country because poverty and unemployment have made it difficult for families and extended families to cope with the orphans. The study could not ascertain an exact percentage of orphans who have lost parents due AIDS, since no statistics which accurately pinpoint the cause of death, is available. Brookes et al (2004) put: it is unlikely, however, that such information would have been accurately reported, because of the potential stigma involved for children whose parents died from HIV/AIDS related illness.

2.5 Child Headed Households

Child headed households are generally considered to be those where the main caregiver is younger than 18 years of age. The constitution of South Africa defines a child as a person younger than 18, which means that the definition of child headed households, is in line with the constitution. Sloth-Nielsen (2004:2) points to the finer distinction made in the relevant literature: "Some authors distinguish between child headed households and adolescent headed households." An appropriate response to the situation would children depend on whether the person heading the household needs more intensive support or less. Sometimes children who still have caregiver, but whose caregivers are terminally ill with HIV/AIDS, though not strictly speaking orphans would be in the category of child headed households. When parent(s) become too sick to do what is necessary, these children assume the responsibility of heading the household. As Sloth-Nielsen (2004:15) puts it: "child headed households in which there is no effective adult caregiver generally do the same as families: work to support siblings, get food, clothing and shelter, and deal with the emotional well-being of their members." This is true, although child headed households may have great

deal of difficulty trying to provide all of this, especially when there is no income with which to sustain the family. The Census Bureau (in Gelles 1995:19) defines a "household" as a housing unit: a house, or a single room. Households can consist of related family members or unrelated persons. The Census Bureau also defines "family" as a group of two or more persons related by birth, marriage, or adoption and living together in a household.

2.6   Pastoral Care and Counselling

Pastoral care is about pastors functioning as caregivers. Gerkin (1997:11) calls pastoral care, the arena within which the pastor is privileged to be with people where they live and breathe, succeed and fail, relate intimately and experience alienation. He notes that this work is done in relation to individuals and communities. According to Campbell (1986:23) pastoral care has come to mean "soul care" by wise persons whose spiritual insight and moral rectitude equip them to lead their "flock" to safety. Sharing the same sentiments Deeks (in Lartey 2003:61) approaches pastoral care from a Christian perspective. He notes that the purpose of pastoral care is "to assist men and women and boys and girls to live as disciples of Jesus". He explores four aims of pastoral care. The first is to encourage people to make their own sense of their experience. The second is to disclose Christian meaning in life. The third is to stimulate men and women to engage in their own conversation with the Christian tradition, and the fourth is to encourage holiness. The above statements show that the pastoral caregiver has a major role to play especially in preaching, educating, and counselling people. A WCC Study Document (1997:92) however, states that pastoral care is a ministry of presence, which every person, not only pastors, can offer. For most pastoral caregivers pastoral care is intertwined with counselling. That is why we often refer to them together as "pastoral care and counselling". Pastoral counselling is the process of helping people to make healthy choices for their lives.

Pastoral care and counselling are associated with the rural image of a shepherd tending the flock. From this image the word "pastoral" is derived. Campbell

(1986:1) points out that some traditional aspects of the pastoral image are not acceptable today, especially those of the priestly function, ministerial authority and helplessness of the Christian "flock". This study focuses the aspects of the pastoral image that emphasize the caring ministry, which is sorely needed when faced by a scourge like HIV/AIDS. Though some people are not infected by HIV/AIDS, nearly all are affected by it directly or indirectly. Therefore, supporting and working with people can make the difference between personal well-being and psychiatric illness. For the church, to leave the buildings and go and suffer with the people where they live, provides the opportunity to reclaim its struggle for human dignity, righteousness and justice. In conceptualising the shepherding model, the author of psalm 23 depicts God as the shepherd who leads people on paths of righteousness. This reveals to us the God who has descended from God's holy place to come to the people and be with them in their distress. This is confirmed in the Gospel of John (10:11 NRSV) where, according to the author of the gospel, Jesus calls himself a "good shepherd who lays down his life for His sheep". This image has meaning for pastoral care today. Jesus showed the world what it means to be a shepherd. In comparison with the hired shepherd a good shepherd is dedicated and powerful, always bearing the well-being of the sheep in mind. The shepherd carries a can of oil to pour onto the wounds of the injured sheep. The shepherd is always present with the sheep, day and night, to protect them from any danger. This kind of pastoral care is needed for HIV/AIDS orphans who are forced to function as heads of households. Lartey (2003:176) emphasizes that caregivers should have an understanding of where people are really coming from.

Pastors are needed as mediators and reconcilers between those infected and affected by HIV/AIDS and those not infected or affected. According to Gerkin (1997:82), to be a good pastor is to seek to understand the deepest longings, the secret sins and fears of the people so that this understanding may bring healing and show the afflicted how the God we serve cares deeply and intimately for them. The problem addressed in this study is how the devastation of HIV/AIDS

causes young, under-aged orphans to have to function as heads of households. The question is whether pastoral care – that of the pastor and that of the entire faith community – has failed, especially in African communities where "ubuntu" added a cultural incentive to care for the needy and destitute. Pastoral questions arising are: where are those uncles, aunts and grandmothers who cared so unconditionally for such children in the past? Why are these orphans not with older caregivers? Is the caring ministry failing today because HIV/AIDS? Most of these questions will be addressed in chapter 5 where pastoral care of the children in question, will be discussed. Where pastoral care or a caring ministry are concerned pointing to NGO's, FBO's and CBO's is not sufficient. In the present situation of HIV/AIDS orphans functioning as heads of households, the study will show that home-based care (HBC) should play a major role.

2.7   Conclusion

The above key terms or key concepts will be expanded on later in this study. These terms give and idea of what is to be expected and worked out more extensively in the remainder of the study. The impact of HIV/AIDS on HIV/AIDS orphans in child headed households leaves families, communities and faith communities with questions such as: how are we going to support these children? Who is going to take up the responsibility of caring for them?

CHAPTER 3
HIV/AIDS ORPHANS AND TRAUMA

3.1   Introduction

This chapter examines the impact of the HIV/AIDS epidemic on children who have been orphaned by HIV/AIDS in South Africa. Since HIV/AIDS is associated with stigma, discrimination and rejection, the study will examine the impact of these factors on HIV/AIDS orphans and orphans in child headed households. Stigma and discrimination associated with HIV/AIDS among family, friends, and in the community lead to the violation of human rights. In this chapter stigma and discrimination will be further explained. This chapter will also explore the experiences of HIV/AIDS orphans as heads of households and argue that these can be deemed traumatic. The impact of HIV/AIDS on the socio-economic situation and education HIV/AIDS orphans will be discussed. This study will also investigate how the children's human rights are violated and will look at the role played by the law and society.

3.2   HIV/AIDS orphans

Some AIDS orphans were born before their parents were infected with HIV. Others were not lucky enough to escape it and were also infected because their mothers did not have access to the programme making use of AZT to prevent paediatric transmission. Some children did not contract HIV/AIDS because their parents had undergone this programme. Especially people in rural areas are either not familiar with the AZT preventive programme or otherwise they have difficulty gaining access to it. In rural areas the most prevalent problems affecting families are education, transport, poverty, unemployment and then lately HIV/AIDS. International policy-makers describe HIV/AIDS orphans as children aged 15 or younger who have lost either their mother or both parents because of HIV/AIDS. An HIV/AIDS orphan is not necessarily also a member of a child headed household. In South Africa child headed households are generally those

33

where the main than 18 (Sloth-Nielsen 2004:1). As previously mentioned in chapter two, an orphan is a child who has lost one or both parents to AIDS. These orphans can be differentiated as (double, maternal, or paternal). *Double orphans* are those whose parents have both died from any cause, not necessarily AIDS. With HIV/AIDS, if one parent is infected, there is a possibility that the other is or will become infected and that both will eventually die. This means that there will be disproportionately large number of orphans as the epidemic advances. Surveys (e.g. UNAIDS 2004:11) show that double orphans are more disadvantaged than single orphans. Sub-Saharan Africa had almost 7,7 million orphans in 2003 and just over 60 percent of those have lost on their parents due to AIDS. *Maternal orphans* are those children whose mothers have died and where it is unknown whether the father is still alive. UNAIDS (2004:11) states that AIDS is changing the pattern of orphaning in Sub-Saharan Africa whereby maternal orphans outnumber paternal orphans in five of the most affected countries. The study shows that the rate of women infected by HIV is greater than that of men. *Paternal orphans* are those children whose fathers have died. These orphans are also called fatherless. It has been discovered that in South Africa one third of paternal orphans do not stay with their mothers. They rather stay with grandparents.

Many infected children come from poor families and do not have access to good medication to relieve symptoms and treat opportunistic infections. Children infected by HIV/AIDS become sick very often. They are generally unhealthy, malnourished and have a low growth rate. Many of them die before they reach the age of 5. Gow & Desmond (2002:62) suggest that already there are approximately 300 000 maternal AIDS orphans. In the next few years this number is expected to grow to devastating proportions. Families who used to care for orphans will feel the effect of this.

HIV/AIDS orphans are those children who lose their parent(s) through HIV/AIDS related illnesses. Manegold & Pather (2004:8) argue that the impact of poverty

34

and war on children is similar to that of HIV/AIDS. Nearly every child in South Africa will in some way or another experience the impact of HIV/AIDS. This, according to Weinreich & Benn (2004:46), constitutes a fundamental problem in the fight against HIV/AIDS.

3.2.1 Stigma and Discrimination

Stigmatisation is a social factor with devastating effects for AIDS orphans. Stigmatisation leads to discrimination, whereby people are unjustly treated and disadvantaged on the basis of their HIV positive status. Some are discriminated against because of their proximity to someone who is HIV positive. Examples of this are orphans and widows. This present-day stigmatisation reminds of the stigma associated with leprosy in Biblical times. The priests had to examine the persons with the disease and would confirm that they were unclean. More humiliation would follow (see LV 13:45-46) when this person had to cover his/her upper lip and cry out "unclean, unclean". They were to live in a secluded area. Hence Leviticus (13:46b) states that their "dwelling shall be outside the camp". They had to wear torn clothes. They were isolated from and by the community because of their disease.

Numerous accounts of discrimination are reported in this country. One of the reasons for this are the myths related to how HIV/AIDS is transmitted. Some of these myths are that HIV can be transmitted by (Van Dyk 2001:32-33):

- living with someone with AIDS and sharing household equipment;
- sharing food, water, plates, cups, spoons, toilet seats, showers or baths with HIV infected persons;
- social contact between school children and sharing school facilities with an infected child;
- donating blood (though HIV can be transmitted through blood transfusions or receiving infected blood, a person cannot become infected by donating blood).

HIV/AIDS still remains the most highly stigmatised disease, which causes the persons infected and affected to become victims of discrimination. Discrimination makes the whole community both those who discriminate and those discriminated against more vulnerable to the spread of the HIV/AIDS epidemic. According to Books (1998:52), many HIV infected and affected people are ostracized by their families. This causes people who are infected to become silent about their positive status. They are concerned that their children, who are not infected, would be rejected by the community and isolated.

Fear of rejection and isolation causes people with HIV/AIDS great pain. This is a great worry to parents, because the stigma and discrimination passed onto their children make their fight for survival so much more precarious. The stigma attached to HIV/AIDS leads to prejudice against these children. On top of the psychological trauma of losing their primary caregivers to a debilitating disease such as HIV/AIDS, AIDS orphans are often stigmatised and ostracized by their communities, friends or peers, sometimes by teachers, and mostly by family members. Girls are more often the ones who drop out of school in order to care for their ailing parents and take care of their siblings. According to Gow & Desmond (2002:5) children suffer physical, emotional, and developmental setbacks as a result of this epidemic.

Stigmatised people are denied the ordinary privileges of social life. Furthermore, if the infected are perceived as "guilty", they may even be held responsible for the consequences of the disease in the community and denied sympathy or (worse) even punished. Because of HIV/AIDS, many children endure enormous anguish as they find themselves without primary caregivers to support and care for them. Some are exploited, beaten, raped, and forced into labour. As a result of the increase in the number of double orphans, the situation has led to the establishment of households headed by children, mostly in their teens. Some households may be headed by children as young as 10 to 12 years old.

Stigmatisation and discrimination cause HIV/AIDS orphans in child headed households to be deprived of basic human and children's rights.

3.2.2 Children's Rights in the Context of HIV/AIDS

Since 1994, the South African government has committed itself to protecting children's rights. According to the United Nations Convention on the Rights of the Child, Article 12 (Gow & Desmond 2002:4), "children have the right to participate in discussion that affect them and due weight should be given to their opinions." On the same note the minister of Social Development and Welfare, Zola Skweyiya stated that people should be very clear that children have fundamental rights that should be protected. In Kenya, the discussion on protecting the rights of children concentrated on unlawful labour activities, sex work and other acts of violence (Ayieko 1997:29). The Committee on the Rights of the Child argues that the impact of HIV/AIDS on children's lives is in fact much wider, as it involves a threat to their civil, political, social, cultural and economic rights (Sloth-Nielsen 2004: 5-6,9). The Committee recommends that measures to address HIV/AIDS should be holistic and rights-based. The primary rights of children as mentioned in Section 28 of the Constitution (see Skweyiya 2002; Sloth-Nielsen 2004:7) are the right:

- to an adequate standard of living;
- to family or parental care, or to appropriate alternative care when removed from the family;
- to basic nutrition, shelter, basic healthcare services and social services;
- to education and leisure;
- to protection from economic and sexual exploitation and child trafficking;
- to be protected from torture or other cruel, inhuman or degrading treatment or punishment.

All these rights are adversely affected by HIV/AIDS.

In situations where children live in remote or rural areas, health and other services are less accessible which leave HIV/AIDS orphans in child headed households very much vulnerable to HIV infection. However, mandatory HIV testing is prohibited and it is regarded as being against the rights of children. The African Charter on the Rights and Welfare of Children states that it will ensure that any child who is parentless or temporarily or permanently deprived of his/her family environment, shall be provided with alternative family care, which includes foster placements or placement in suitable institutions for care of children (Article 25[2]). This will be done only if the children are willing.

These rights of children mentioned in Section 28 are applicable to children who grow up in child headed households. For the purpose of the Constitution, anyone who is younger than 18 is considered to be a child (Section 28[3]). Though presently there are some orphans who have no proper documentation, Section 28(1) (a) states that every child has the right to a name and nationality by birth. Birth registration is important for access to social grants. Sloth-Nielsen (2004:14) points out that also in this regard children infected or affected by HIV/AIDS are often discriminated against. Strict measures prohibiting discrimination of this kind, will benefit infected and affected orphans in child headed households.

3.2.3 Child Headed Households

The available information on child headed households is limited. As the prevalence of HIV/AIDS increases, the number of orphans who function as heads of households will also increase. Child headed households are formed when bothers and sisters insist on staying together and refuse to move away from their deceased parent's home. It has been mentioned that the number of infected women is greater than that of men. Hence there is majority of women willing to take care of orphans these children will be more vulnerable than children with parental care when these caregivers died. Deborah Ewing (Gow & Desmond 2002:83) argues that employed adult siblings of orphans may head households. Other heads of households may be school-going older siblings, children caring

for each other with adult support from another household, or children caring for a dying parent with no adult support. In circumstances whereby children have become caregivers to adults with HIV/AIDS, their childhood is effectively sacrificed. Hence there are community organisations taking the initiative of training and supporting these children who are fulfilling adult roles at the expense of their own security and development. Children in poor communities who do not have adult caregivers or whose caregivers are dying, are especially vulnerable. This is because there is no adult to give them support and security. Or their predicament is due to the fact that the communities in which they live and are growing up, face extreme poverty. As mentioned earlier, child headed households in which there is no adult caregiver, generally functions the same as regular families: they work to support siblings, to obtain food, clothing and shelter, and they concern themselves with the emotional well-being of their members. Orphans in child headed households face particular challenges and exclusion. These challenges include:

- a serious threat to education because of poverty;
- difficulty in obtaining food and shelter;
- a high risk of being sexually abused by relatives and neighbours;
- the threat of child prostitution and child labour;
- difficulty in getting birth registration done and in procuring healthcare and social security benefits.

They may also experience property grabbing by families and communities.
Some of the experiences of HIV/AIDS orphans as heads of households include the psychological trauma of witnessing a parent's illness, of dealing with death, the absence of adult guidance and mentoring, and the unmet need for love and security (Sloth-Nielsen 2004:3). They have difficulty in getting or continuing with schooling and/or obtaining social grants. It is extremely difficult for adolescents who themselves are still in transition to adulthood; to assume the adult role of raising younger siblings after the primary caregiver has died.

The Children's Bill makes provision for the legal recognition of child headed households as a type of family unit in our society. This gives the orphans in child headed household the right to stay together without them being distributed among families. The problem encountered by the orphans is that they cannot become foster caregivers to their siblings. This is why the law commission has introduced a mentor system. These mentors will deal with a number of matters concerning child headed households. Among others they will administer the day-to-day functioning of the family unit. As they will undergo training, they can provide emotional and psychological support, assist the children to obtain birth registration documentation, provide advice and counsel, as well as formally receive grants for those who are unable to go and get it themselves.

3.2.3.1   Challenges

Orphans in child headed households face quite a number of challenges. Studies (Forster 2003:503; Uys & Cameroon 2003:177; Sloth-Nielsen 2004:2) have shown that the greatest challenge faced by these children is finding sufficient food. In addition they struggle to pay their school fees; they lack the money to buy school uniforms and other clothes; they do not have money for transport or health care; their housing is insufficient and often lacks warmth. These children need the support of family, but due to the stigma associated with HIV/AIDS, the family is unwilling to care for and support them. Though entitled to social grants, the orphans have problem accessing these benefits, often because they do not have the necessary documentation and because they are under the age of 21.

3.2.3.2   Identity, Birth Registration and Documentation

Under the Registration Act every citizen in South Africa has to be registered. Such registration as a citizen makes access to the available state resources possible. Sloth-Nielsen (2004:25) states that "receiving social security, placing a child in foster care, and fulfilling many other children's rights depends on registration of birth and gaining an approved identity document." These documents will also enable the orphans in child headed households to inherit the

family property after their parents have died of HIV/AIDS. When both parents have died children are left to fend for themselves and are vulnerable to relatives or neighbours who often dispossess and evict them from their parents' property.

3.2.3.3 Social Grants

Household income indicators (Gow & Desmond 2002:81) show that about 12 million of the 17 million children in South Africa are living in poverty. Nine percent of these children live in households where there are no parents or grandparents. The Department of Welfare's National Strategic Framework for children infected and affected by HIV/AIDS aims at delivering an effective and appropriate care system, encouraging families and communities to take care for HIV/AIDS orphans and other vulnerable children. The Department has committed itself to transforming social security in order to address child poverty with particular regard to the impact of HIV/AIDS on children (Gow & Desmond 2002:81).

As a way of alleviating poverty among orphans, child headed households, and other children who qualify in terms of certain criteria; the government has allocated social assistance in form of money. This money is given to caregivers who look after the children. Social grants have three categories related to children: Child Support Grant (CSG), Foster Grant (FG), and Care Dependency Grant (CDG). All these grants play a vital role in caring for children. Children orphaned by HIV/AIDS may also benefit from these grants, but it depends on which category the child belongs to. Poverty, exacerbated by HIV/AIDS, is causing a growing number of children to be eligible for grants. Although these grants are meant for vulnerable children there are people who are helping themselves to the money at the expense of the children for whom it was intended. A young girl of 16 who is still at school reports that her aunt does not give her a cent or buy her anything. Instead the aunt pays off her cash loans with the foster grant. A social worker sent to investigate has confirmed that the pay card remains with the cash loans people. The aunt picks up the card on payday and then takes it back after she has received the money. Arrangements were

41

made that the community based care coordinator take responsibility for collecting the money and reporting at the end of every month how it was spent for the child.

The Child Support Grant is paid to the persons responsible for the child's primary care. It is meant for children living in poverty in South Africa. The persons who receive the money may be the parent, a relative or an unrelated member of the community. Presently the child support grant is R180 and is available to children younger than 14 years. Some of the difficulties faced by orphans in child headed households and other vulnerable children is getting access to the grants since there is no responsible adult to pick up the money (see Sloth-Nielsen 2004:30-31).

The Foster Care Grant is to benefit children who have been formally placed in the care of foster parents by the children's court. In the case of orphans in child headed households, community based caregivers are granted permission by the court to care for these children, but only if a report from a social worker accompanies the application. The amount payable is R560. This may not cover all their costs, but orphans could at least have a chance to buy food and some clothes. The Foster Care Grant helps somewhat to alleviate poverty among orphans in child headed households.

The Care Dependency Grant is meant for children up to 18 years old with severe disabilities who require permanent home-based care. It pays R780 per month. This grant is for severe mentally and physically handicapped children (Gow & Desmond 2002:89; Sloth-Nielsen 2004:29). This grant is means tested, which means that the combine annual family income must not exceed R48 000 per annum after deductions. Children at terminal stages of AIDS are eligible for this grant, though there is no formal policy to guide practitioners as to whether and when HIV-positive children may be awarded this grant (Gow & Desmond 2002:89).

Social grants have played a major role in education since quite a number of orphans who have gained access to grants are able to buy school uniforms, pay their school fees and at least have some money to take to school.

3.3   Socio-economic Context

The prolonged illness of parents with HIV/AIDS affects a household's economy. The family income decreases, where at the same time much more has to be spent on medical treatment. AIDS morbidity and mortality have different effects on the household economy and the well-being of children. When compared to other illnesses, it is found to induce a particular form of stigma and discrimination (Bray 2004:46). So far the link between HIV/AIDS and poverty is undisputed. People in poverty stricken circumstances are more vulnerable to infections such as TB and AIDS. For example, HIV/AIDS has fuelled TB epidemics in areas where TB was already prevalent. According to Uys & Cameron (2003:163), poverty is not just physical. Instead it impacts on social and economic relationships. They also noted that considerable numbers of impoverished children contract HIV/AIDS on account of the transmission of the disease from mother to child. A child born in a poor family inherits all the ills connected to poverty. These children are unfortunate in not being able to have access to antiretroviral treatment and most of them die of AIDS related illnesses at a young age. The circumstances, under which child headed families live, are conducive to this. Rosa & Lehnert (2003:1) are of the opinion that the overall needs of these children far exceed the emotional and socials needs of children who have experienced the trauma of losing their parents.

3.4   Impact of HIV/AIDS on Education

This section examines the impact of the HIV/AIDS epidemic on education in relation to HIV/AIDS orphans in child headed households. "More that 113 million school-age children are out of school in developing countries, two-thirds of them girls. Of those who enter school, one out of four drops out before attaining literacy" (World Bank 2002:XVI). The impact of HIV/AIDS on the entire education

system is evidenced primarily in the deterioration of educational services. Teachers stay away (are sick) and die because of HIV/AIDS. This adversely affects orphans as it affects all children. Orphans are less likely to be in school and more likely to fall behind or drop out, which of course compromises the development of skills and abilities and future prospects. On numerous occasions HIV/AIDS orphans are scorned by other children, discriminated against and isolated to such an extent that they find it better to stay away from school. Others feel badly when they have no money for a school uniform, to pay their school fees, or pocket money to take to school. The stress of their situation takes its toll on orphaned children's education. For households that have been crippled by HIV/AIDS, it is not easy to cope with the fees of primary education. Hepburn (2002:91) explains some reasons for this as follows:

- the loss income from employment and activities;
- in rural areas, a reduction in farming which decreases income generating potential;
- high costs for health care and medication;
- a growing number of households affected by AIDS are headed by children.

In order to supplement household income, HIV/AIDS orphans may drop out of school and engage in other means of generating funds. They often become vulnerable to sexual and physical exploitation and HIV infection.

3.5   Trauma of HIV/AIDS

It has become clear thus far that many of the experiences of HIV/AIDS orphans can be deemed and are experienced as "traumatic". Therefore it is necessary to take an in-depth look at what trauma is and what the effects of traumatic experiences may be. Gibson et al (1995:63) put it as follows: "Trauma is widespread in society and can have serious effects not only on those exposed to it, but also to those who offer help. Even organisations set up to help survivors of

44

trauma can be badly affected unless they build mechanisms to look after themselves."

3.5.1   What is Trauma?

Several answers to this question have been given in order to describe and explain the meaning and consequences of trauma for human beings. Cairns (1999:7) defines "trauma as a psychic wound resulting from an event so horrifying that the individual is unable to assimilate it into normal conscious awareness." The word trauma comes from the Greek word *traumata*, which means "wounds". Physical wounds are visible whereas psychic wounds are invisible in day-to-day encounters and can be detected only by way of the changes that take place after the traumatic experience. Victims of trauma are those members of society whose problems represent the memory of suffering, rage, and pain in a world that longs to forget. The victims of childhood trauma constantly relive the atrocities of the past as adults, which makes it difficult for them to live a normal life. The traumatic event thus destroys the belief that one can be oneself in relation to others. Feelings of guilt may be severe especially when the survivor has been a witness of the suffering or death of other people. Some of the orphans who lost their parents feel guilty for not having been able to save their parents or for failing to fulfil the requests of the dying person.

From a slightly different angle trauma can be described as a wound we sustain when we are exposed to experiences so horrifying that it overwhelms our capacity to process the experience, which later it leads to the physiological and psychological response known as traumatic stress. Traumatic events shatter the sense of connection between individual and community. They also impel people to withdraw from close relationships. Hence Herman (1997:56) argues that traumatized people suffer damage to basic structures of the self. They loose the trust in themselves, in other people and in God. The impact of being among people, who do not appreciate one's presence, has a severely negative effect on HIV/AIDS orphans. Factors such as a combination of stigmatisation and having

45

to drop out of school, friends changing, an increased workload, discrimination and social isolation all mentioned by Bray (2000:45) function to increase the stress and trauma of the death of parents that HIV/AIDS orphans experience. When traumatic loss occurs during adolescence, these young men and women become emotionally confused. In other words they require a great deal of attention and support. Here pastoral care can play a vital role. According to Granot (2005:89) it is critical to monitor adolescents and keep close track of their emotional state so as to identify the distress signals when intervention is required. Research among youth has indicated that the rate of suicide has increased since the 1980's when HIV/AIDS was identified in South Africa. When discovering that they are HIV-positive, young people wonder how they are to face their family, community, and friends. Then when there are no answers the solution seems to be suicide as the only way out. Or else, when the adolescents are confronted with troubles and questions they are unable to solve, they act out by resorting to "solutions" like alcohol, drug abuse and violent criminal behaviour. Therefore quick intervention is required before great damage occurs.

Herman (1997:159) points out that it is necessary to establish a safe environment for people who have experienced trauma in order to restore a sense of power and control over the situation. Survivors of trauma feel unsafe in their bodies. Their emotions and their thoughts feel out of control. Their natural support systems such as family, lovers, and friends should be mobilised and they can be introduced to voluntary self-help organisations to assist them. Establishing safety begins with regaining a sense of control over the body and gradually moves outward toward regaining a feeling of control over the environment. This includes a safe living situation, financial security (grants), mobility and social support.

The acutely traumatized person needs a safe refuge. For example, if orphaned children are in homes where they do not feel safe, they move out and end up joining those who are already on the street. Families have a major role to play in situations of trauma. Supportive family members can make a big difference to the

life of a traumatized child. The psychological effects of losing a parent to an illness like HIV/AIDS are severe and have long-term implications for a child's behavioural development. Having endured the loss of parental support and nurturing, many orphans experience anxiety, depression, and despair. Further complicating these emotions is the fact that siblings are often divided among several households within the extended family to mitigate the economic burden of caring for orphans. In addition to the trauma of loosing parents, relatives and neighbours often contribute to the children's despair by taking their property and/or inheritance from them and leaving them more vulnerable to exploitation (Hepburn 2002:93). The trauma of parental illnesses and death affects their schoolwork to the extent that they often have to repeat the school grade. The Diagnostic and Statistical Manual IV of the American Psychiatric Association (1994: 427-429) states that the reaction to trauma and stress are known as post-traumatic stress disorder (PTSD). Broadly speaking, PTSD includes avoidance (people actively avoid any reminder of the traumatic event), hyperarousal (being in a state of constant alertness and physiological arousal, which affects one's ability to sleep and causes an exaggerated startle response), emotional constriction (the inability to feel the full range of human emotions) and intrusive recall (flashbacks or repetitive images or thoughts associated with the event) (Levin 2001:3).

Trauma does not only affect the survivors of trauma. It also affects those close to the survivor and broader community. All symptoms mentioned above have been found not only in trauma survivors but also in family members and witnesses of trauma. Counsellors and therapists who work with trauma victims may in time develop PTSD symptoms themselves. These people are said to be suffering from secondary trauma (Gibson et al 1995:68). Trauma work first and foremost is about listening deeply, recognizing the past in present reactions of trauma, about understanding relationships of all kinds including those between caregiver and client. This study will elaborate more on traumatic work when dealing with pastoral care and counselling in chapter 6.

3.6 Summary

 In this chapter it is has become clear that stigma and discrimination has played a major role to the problems of HIV/AIDS orphans. This led to some orphans in affected households dropping out of school because their friends have changed and they have to endure scorn from other students and some teachers. Some adolescents take care of their dying parents without any support from adults. They also take care of their siblings when their parents are still sick and after the death of the parents. Quite a number of infected and affected children come from poor families. They lack access to medication, which could relieve symptoms and opportunistic infections. Often children from these families are malnourished and likely to become sick. Children in poverty stricken households are also vulnerable to all sorts of ills connected to poverty. They do not have access to antiretroviral medication because of economic constraints. The problem encountered by HIV/AIDS orphans is they cannot officially become foster caregivers to their siblings until they have reached the age of 21. Up till now the mentors are the ones who receive the grants for orphaned children. Quite a number of HIV/AIDS orphans as heads of households encounter problems with access to social grants and inheriting the family property, because their documentation is not in order.

The department of education is now facing a new challenge. HIV/AIDS infected teachers stay away from school because they are sick. As far as the children are concerned, some adolescents are leaving school in order to look for jobs that will help them obtain food for their households. In this study it is shown that the death of parents due to HIV/AIDS leaves orphans with increased stress and trauma. An adolescent left by parents to head the household becomes emotionally confused, stressed. Many of these factors challenge the development of the children who have become orphans on account of HIV/AIDS and are forced to function as heads of households. The following chapter will highlight the psychosocial issues of HIV/AIDS orphans as heads of households.

CHAPTER 4
PSYCHOSOCIAL FACTORS

4.1   Introduction

Psychosocial theory, according to Newman & Newman (1999:33) addresses growth across the life span from infancy to old age. Issues of central importance are identified and differentiated. Themes of the different stages of human development are traced. The assumption is that individuals have the ability to contribute to their own psychological development at every stage of their lives. They have the ability to integrate, organise, and conceptualise their experiences in order to protect themselves, to cope with challenges, and to direct the course of their lives. Psychosocial theory also contributes to the cultural growth of every individual.

4.2   Psychosocial development

Psychosocial theory is viewed as a product of the interaction between the individual needs, abilities and social expectations and demands (Newman & Newman 1999:34). In the same vein Loughry & Eyber (2003:1) see "psychosocial" as a close relationship between psychological and social factors. Psychological factors concern emotional and cognitive development (the capacity to learn, perceive and remember), whereas social factors are about the ability to form relationships with other people and to learn and follow culturally appropriate social codes. According to Erik Erikson's model of the eight stages of development each stage is unique and leads to acquisition of new skills. During each stage the person is confronted with a unique problem, which requires the integration of personal needs and skills with the social demands of one's culture (Newman & Newman 1999:284). The box below represents Erikson's psychosocial development stages. One will note that the periods of life are given names such as oral-sensory or puberty and adolescence, without specific ages.

Figure 1

Stage	1	2	3	4	5	6	7	8
8. Maturity								Ego integrity vs. Despair
7. Adulthood							Generativity vs. Stagnation	
6. Young adulthood						Intimacy vs. Isolation		
5. Puberty and adolescence					Identity vs. Role confusion			
4. Latency				Industry vs. Inferiority				
3. Locomotor-genital			Initiative vs. Guilt					
2. Muscular-anal		Autonomy vs. Shame, doubt						
1. Oral-sensory	Basic trust vs. Mistrust							

Erikson's (1963:245) model of psychosocial stages of development

Source: Erikson, 1963. Childhood and Society.

These stages play a vital role in the development of human beings. Erikson's model will be applied to the situation of children who lose their parents and family systems due to HIV/AIDS during the younger stages of their lives. Conclusions will be drawn as to how the events surrounding HIV/AIDS may affect the development of these children, since infants use their mothers or other primary caregiver as a social reference.

The first stage in Erikson's model is that of *basic trust versus mistrust*, which is also known as the *oral-sensory* stage. The psychosocial crisis, according to

Newman & Newman (1999:169) is the struggle between the positive and negative poles of a critical inner dimension. Trust versus mistrust fundamentally focuses on the infant's sense of connection to social world. Newman & Newman (1999:169) argue that trust is about the predictability, dependability, and genuineness of relationship as one person discovers those one traits in another person. This trust is the faith that relationship will survive uncertainties and unpredictability should they occur. Trust is the integrating force, which helps to synthesize emotions, cognition, and action under irregular circumstances. Infants have emotional trust in people or they may mistrust them. Mistrust arises when an infant lacks confidence in the caregiver and doubts his/her own lovability. Infants show "startled" reactions to loud noises and mono reflexes to sudden loss of support. In order to promote the building of trust in child caregivers should try to minimise the infant's exposure to stimuli which evoke reflexes. Such a caregiver should be able to comfort and reassure the infant that he/she is in tune with the infant's needs and able to respond appropriately. When infants are cared for by adolescents who are little more than children with needs themselves, the babies will most likely be neglected at times and left without anyone to care for their needs. Infants then discover that reliable care is physically and psychologically unavailable.

Parents play an important role in promoting the psychological growth of their children. They also ensure the safety of children and protect them from environmental dangers. In an African context mothers carry infants of up to 18 months or older on their backs, even when they are already able to walk. This is one way of protecting them from danger though this may limit the child's exploratory behaviour. HIV/AIDS orphans who are responsible for the household and caring for siblings are inexperienced in child rearing. They cannot give infants what they need in terms of physical protection. Parents also play a major role in promoting the emotional and cognitive development of the infant. Boeree (1997:5) argues that if parents can give a newborn a degree of familiarity, consistency and continuity, then the child will develop the feeling that the world,

51

especially the social world, is a safe place to be, that people are reliable and loving. If these aspects are not present in the life of a young child, the social world will be experienced as threatening and approached with suspicion. At the other extreme, parents who are over protective of their children cause what Erikson calls sensory maladjustment. Children, whose balance tips over to the side of mistrust, develop the unhealthy tendency to withdraw, which is characterized by depression paranoia and possibly psychosis (Boeree 1997:6).

Stage two has to do with self-confidence or self-esteem and is about feeling confident. The crisis at this stage is *autonomy versus shame.* Parents are there to encourage toddlers when they develop language and muscle control. Children absorb vast amounts of new information about world and self. If parents are overprotective or disapproving of the toddlers' acts of independence, the children will feel ashamed of their behaviour and develop doubts about their abilities. Stages 1 and 2 are critical for social formation, or in African terms, for establishing ubuntu in a child. When parents die at these stages of development and the formation of social skills and interaction, and there is no adequate replacement of the primary caregiver, the child will most probably regress.

Stage three represents the crisis of *initiative versus guilt.* The task of the child in this stage is to learn initiative without acquiring too much guilt. Boeree (1997:7) refers to initiative "as a positive response to the world challenge, taking on responsibilities, learning new skills, feeling purposeful." It is the attempt to make non-reality a reality. Parents should encourage children to experiment, but should also be consistent with their discipline. Then children will learn to accept that certain things are not allowed while at the same time they do not feel shame when using their imagination and engaging in make believe role-play. However, if this process is approached harshly and too abruptly children will feel guilt about their feelings. The ideal is that children reach early school age with a strong sense of themselves as unique individuals. At this age they like to draw attention by asking questions. Pennington (1986:39) argues that during this stage sex role

and other role definitions, for example social class begin to take shape. Failure to develop a sense of purpose results in a lack of independence and a persisting sense of guilt over this failure. When others are unhappy or there is conflict they tend blame themselves. The psychosocial crisis of this stage highlights intimate and emotional development (Newman & Newman 1999:28). Children should develop a strong internal moral code, which makes constant discipline unnecessary.

At stage four the psychosocial crisis is *industry versus inferiority*. This stage is also known as latency or school age. Children form relationships with teachers and other adults. The developmental task is to learn friendship skills, self-evaluation and team play. In the previous stages parents played the most important role in the development of the children, but now teachers, peers, other family members and other members of the community also have a great influence. Peers can encourage children in the acquisition of skills, but they may also receive some negative input from others. Children in this stage become interested in real life roles and play at being doctors, nurses, fire fighters, pilots and the like. They gain self-confidence and competency. When parents die at stage 3 or 4 when the children are trying to envision themselves as adults, they tend to feel helpless and discount their success. Often they are not positive about the future. According to Boeree (1997:8) the role of parents is to encourage, teachers to care and peers to accept. It is vital that "children must learn the feeling of success, whether it is in school or on the playground, academic or social" (Boeree 1997:8). It is especially devastating for HIV/AIDS orphans in these stages when they have to face stigma, discrimination, isolation and scorn by the peer group, community, family members and some teachers. Worst of all is the loss of the parent(s) who were supposed to be their guide, give them courage, nurture and teach them how to cope with the basics of life. If children at this stage do not experience success they will have trouble developing a capacity for industry and will develop a sense of inferiority or incompetence. Other sources of inferiority are: racism, sexism, and other forms of discrimination.

Children, who already see themselves as inferior or incompetent in the eyes of other, can become totally apathetic. Role models who are able to help HIV/AIDS orphans to tip the scales to industry rather than inferiority are sorely needed so that these children can develop competency.

Stage five is adolescence. It begins with puberty and ends around 18 or 20 years of age. The emphasis of this stage is on learning to cope with the demands of rapid physical growth. Gillis (1994:72-75) mentions three stages of adolescence: child adolescence (±12-14 years), mid-adolescence (boys ±14-16yrs; girls ±13-16 yrs), and adult adolescence (±17-20). The task during adolescence is *ego identity versus role confusion*. Kail & Cavanaugh (1996:215) call adolescence a "recent cultural invention". The reason is that for much of recorded history, "children moved directly into adulthood, when they were considered to be young adults." As adolescents approach the adult world they struggle to achieve an identity which will allow them be well prepared to face new developmental challenges such as intimacy, and sharing relationships with others (Kail & Cavanaugh 1996:260). Adolescents are in search of their ego identity, which are a conscious sense of individual uniqueness as well as psychosocial sense of well-being (Adam & Berzonsky 2003:206). This stage is marked by rapid changes. Although these changes may make them feel like adults, they are not ready to assume the tasks of adults, such as for example being parents. Pennington's (1986:41) states that the search for one's "true self", or attempts to answer the question "who am I?" preoccupy teenagers. When parents die at this stage of the children's lives, adolescents have to take responsibility for siblings, which may be traumatic for both the adolescent and the younger children. While other youth are involved in dating relationships, HIV/AIDS orphans as heads of households have to look after siblings and assume adult roles and responsibility.

Adolescents in early and mid-adolescence rely more heavily on peers than on family. Later in adolescence they gain the confidence to rely more on their own priorities when choosing friends and initiating relationships. Then they are less

open to influences and manipulation from the peer group. In situations of stress the support of peers may not be as strong or as present (Loughry and Eyber 2003:15). However, the stability and support provided by the family is significant. Teachers should be encouraged to genuinely care for all children. Children should get to know the feeling of success, whether it is in school or on the playground, academically or socially. This does not happen for HIV/AIDS orphans who have to face stigma, discrimination, isolation and scorn by their peer group, the community, family members and also some teachers. If parents who are supposed to guide, encourage, nurture and teach the basics of life are not there, these children are left to their own devices in extremely stressful circumstances.

In preparation for the transition from childhood to adulthood, a number of so-called "tasks" or challenges in each area of development must have been completed for the young person to be prepared for a successful adult life. According to Gillis (1994:71) these tasks are not simply chores but a series of highly personalised experiences that will help adolescents to cope with obligations, demands, and pressures of adulthood. These tasks include:

- adjusting to changing body growth;
- mastering new, complex ways of thinking;
- dealing with awakening sexuality, and the powerful drives which company it;
- achieving a satisfactory sexual identity;
- learning to relate to peers and to society in a mature way;
- attaining emotional independence from parents, family and other adults;
- accepting adult responsibilities, and socially acceptable values and behaviour;
- choosing a vocation, and establishing economic independence;
- preparing for marriage and family life.

All these "tasks" are steps through the development of adolescents from which they will emerge with a positive or negative self-concept. Self-concept, according

to Gillis (1994:79), is a "general term used to describe the way in which individuals perceive themselves." Self-concept is used interchangeably with "self-esteem", which refers specifically to the personal assessment of the value or worth individuals place on themselves. This value according to Gillis (1994:79) can be expressed either positively, for example: "I am a capable person" or negatively as in "I'm a loser" or "people don't seem to like me".

Depression is common in adolescence, because of the many pressures they face. The pressure of being a teenager and having friends, who do not understand them, pressure from parents or other caregivers. For those who have no parents due to HIV/AIDS there are the pressures of having to take care of oneself and others, and of being ostracized by peers and isolated from family and community. In the case of HIV/AIDS orphans who become heads of households depression is triggered by the loss of parents through the debilitating disease of AIDS. Furthermore they have to take on a role far above their abilities and they have to do so in circumstances of poverty, worrying every day about finding something to eat. Depression deprives teenagers many rewarding experiences and interactions.

As adolescents grow they are faced with physiological changes in themselves and the tasks of adulthood lying ahead of them. HIV/AIDS orphans have prematurely been forced into these tasks. Erikson (1963:235) calls adolescence a state of "moratorium" which means a psychosocial stage between childhood and adulthood, and between the moralities learned by the child and the ethics to be developed by the adult.

Stage six the strength acquired from previous stages is tested. Young adults are eager to fuse their identities with that of others. They are ready to commit themselves to affiliations and partnerships and to develop the ethical strength to abide by such commitments. The psychosocial crisis at this stage is *intimacy as opposed to isolation.* According to Boeree (1997:10) intimacy is the ability to be

close to others, as lovers, friends, as a participant in society. Those who have successfully negotiated this, carry with themselves for the rest of their lives the psychosocial strength Erikson calls love. This love does not only include the love to be found in a good marriage, but also the love between friends and the love of one's neighbour and compatriot. This stage sometimes is regarded as the late adolescence. The crucial task in late adolescence is the search for a long term commitment to a marital partner or other companion with whom one can express one's need for intimacy and care for the needs of the other (Gerkin 1997:175). There is a significant number of orphaned young adults who are heads of households who mostly live in poverty, have not income and rejected by their families on account of the stigma of HIV/AIDS. The focus of this study, however, is not on young adult heads of households, but on children who experience their lives as traumatic. Therefore I will not elaborate further on this particular stage except just to point out that, if this stage is built on the strengths acquired in the previous stages, and young AIDS orphans had little opportunity to acquire strengths, the stage of young adulthood is bound to be very difficult, of not disastrous for such a person.

Stage seven is the phase middle adulthood. The psychosocial crisis at this stage is *generativity as opposed to stagnation*. The primary concern of generativity is to establish and guide the next generation. This stage includes the period in which individuals are actively involved in raising children. Generativity, according to Erikson (1963:240), is an essential on the psychosexual as well as psychosocial schedule. Erikson disputes the fact that having or even wanting children qualifies one to "achieve" generativity. Boeree (1997:11) also agrees that there are other ways to attain generativity, such as teaching, writing, invention, the arts and science, social activism and contributing to the welfare of future generations, for example. Concerning HIV/AIDS orphans who have been abandoned by extended family members, these uncles and aunts seem to have tipped to the side of stagnation rather than generativity in their attitude towards a younger generation in need. Boeree (1997:11) points to another crisis of middle adulthood, namely

the "midlife crisis", where people want to imagine younger than they are. Those who resolve the crises of this stage successfully will have a capacity for caring that will serve them well throughout their lives.

Stage eight is about the psychosocial crisis of ego integrity versus despair. Some people do not reach ego integrity because of problems earlier in life, which have retarded their development. Characteristics of ego integrity are memory, reasoning, information processing, problem solving abilities and the adult capacity to introspect and to assess his/her personal history (Newman & Newman 1999:471). These characteristics are called "intellectual capacities" and they influence the adult's ability to remain involved in productive work. Social scientific research has established that satisfaction in marriage contributes significantly to psychologically well-being. Integrity, as mentioned in Erikson's theory, refers to the ability to accept the fact of one's life and face death without fear (Newman & Newman 1999:494). This stage is the result of all the precious psychosocial crises, which, if resolved successfully, have contributed to ego strength.

4.2.1 Psychological Factors

This section investigates some of the major issues touched on in psychological studies on the impact of HIV/AIDS on orphaned children. Here the problems experienced by HIV/AIDS orphans as heads of households will be compared to those of children who have been orphaned by other circumstances in order to ascertain whether HIV/AIDS orphans experience trauma on a larger scale than orphans in other circumstances. Wilds (in Bray 2003:46) commenting on the limited availability of literature on this issue in both Africa and the USA, concludes, "that there is not yet a definitive answer to the question whether losing a parent to HIV/AIDS places children at increased risk for psychosocial adjustment difficulties." Bray (2003:46) points out that, according to some studies, there are no heightened levels of emotional and behavioural problems amongst children who have lost parents to AIDS related illnesses relative to a

comparison sample from same community. Within psychology two discourses exist: one emphasizing the vulnerability of children and the other emphasizing their resilience. Some of the factors that assist children in coping, for example are parental presence, religious, or political ideology and personal coping styles. Studies done with other children in so-called "difficult circumstances" such as refugees, and children of war, show similar signs as HIV/AIDS orphans. Forster (2002:504) confirms this by saying that there are many similarities between the damage experienced by children of war and violence and the recurrent trauma experienced by children affected by AIDS. In their study, Loughry & Eyber (2003:7) discovered that "many children despite experiencing extremely distressing and sometimes horrifying events grow up to be healthy adults." Some children appear to bounce back after stressful events. Bray (2003:46) suggested that different factors are responsible for promoting resilience and protecting children from negative outcomes. For this reason, the context in which the traumatic experience takes place can be as important as or even more important than the experience itself. If favourable conditions can be created, then there is a good chance that children will be able to successfully overcome the trauma of losing a parent. The question therefore is whether the presence of certain securities such as shelter, a consistent caregiver, friendship and/or economic balance can make a critical difference to the impact of parental death on children.

Tedeschi & Calhoun (1995:2) have argued that "many people view the aftermath of the event as something that has benefited them. But to others it creates problems that may result in stress." In this regard the HIV/AIDS epidemic has contributed to psychological problems, especially among HIV/AIDS orphans in child headed households. This may be evidenced from early childhood where children show signs of distress such as disturbed eating patterns, excessive wetting of the bed, and random crying. Adolescents may show signs of distress such as bulling others or engaging in drug and alcohol abuse. These signs indicate that losing their parent(s) and also being rejected by the extended family has an impact on these children and is emotional disturbing to them. It is also a

problem when children are excluded from information and decision-making. Marcus (in Bray 2003:46) points out that children are frequently excluded from conversations about the imminent death of a parent owing to cultural norms about what is "right for children". "We do not discuss that with children". Granot (2005:12) does not see this exclusion as too much of a problem: "The child absorbs the beliefs of the culture in which he/she is raised and usually accepts the answers it provides. This cultural and religious framework of beliefs helps adults, grapple in the aftermath of a loss."

The greatest hardship on orphans, according to Granot (2005:130), is not the death of a parent but the experiences of abandonment by the surviving parent, who does not function as a parent. This almost always happens when mothers die first. The fathers often vanish and leave the children to fend for themselves. On the other hand, the child might also feel abandoned because of prolonged "pathological grieving" whereby the mother is engulfed by the shadows of death. Regarding orphans who function as head of households it is the abandonment by the extended family members that leaves its mark. The children are left with unanswered questions. "What have we done to deserve this?" "What did our parents do wrong?" "Why do we have to suffer like this?" This has a psychological impact on the children. First they experienced the death of both parents and then the abandonment by the extended family. Their entire world is shattered. It makes them to feel that they do not belong to anybody, that there is no one to care for or look after them, no one to guarantee their well-being and love them (Granot 2005:135).

It has been found that, due to HIV/AIDS related illnesses of parents; there are particular changes in children's behaviour (Books 1998:54,61; Skweyiya 2002:2). In addition, orphans were found to exhibit internalised behaviour changes such as depression, anxiety, and low self-esteem as well as sociopathic behaviour such as stealing, truancy, aggression and running away.

4.2.1.1 Emotions

"Usually when people are sad, they don't do anything. They just cry over their condition. But when they get angry, they bring about a change" Malcolm X (1925-1965) – American Civil Rights Activist.

This section will examine the emotional experiences of HIV/AIDS orphans as heads of households in the context of death of their parents. Emotion is about feeling. People understand when someone is happy or sad. Judging by their emotional expression one can tell what the state of other person or animal is. For example, both animals and humans signal their readiness or willingness to help, fight, or run through gestures, postures, and facial expressions. Fear and anger produce a greater acceleration of heart rate than does joy. Feelings help individuals to be able to enter into the "world" of others. Feelings permit individuals to be sensitive, caring, and understanding, especially in this case to the experiences of HIV/AIDS orphans as heads of households. David Matsumoto (1994:117) states that people need to be mindful of two things concerning emotion: one is the *experience* of emotion and the other is the *expression* of emotion. Since the focal point of this study is the experiences of HIV/AIDS orphans as heads of households, I will now highlight how these children express their feelings or emotions. The most common emotions they experience are sadness and depression. As Payne et al (1999:23) put it "the depression of the loss is likely to be variable, with particular events or memories triggering painful waves of sadness, which although they diminish over time can still recur years later." Depression, where people are unable to undertake normal everyday activities, may lead to feelings of worthlessness with the result that suicide may be attempted. Children, like adults, go through emotional turmoil. They need time, assistance and the support of those closest to them, especially their parents. However, in their study Loughry & Eyber (2003:7) discovered that many children, despite experiencing extremely distressing and sometimes horrifying events, grow up to be health adults. Some children really are resilient.

61

The loss of parents and other important people in the lives of HIV/AIDS orphans as heads of households leaves a void in their lived which also affects their relationships with friends, family and/or community. Stigma and discrimination have created a wall that separates the HIV/AIDS infected and affected orphans as heads of households from these potential sources of social support. Traumatic loss raptures the ordinary sequence of generations and defies ordinary social conventions of bereavement. Bereaved people may experience disturbances in concentration and lack of motivation, which makes it difficult to understand new information or engage in complete cognitive activities (Payne et al 1999:25). On the other hand bereaved people often feel jumpy, anxious, even fearful. After all, their whole world has been overturned and all stability and certainty have gone with the only one they loved. This feeling is common in as much one may feel that he/she is literally going mad with grief, or one may feel the dead person's presence, spot them in the street or hear them in the other room. Some individuals find it so painful that wish they could join the departed. These phenomena are a natural part of coming to terms with death. HIV/AIDS orphaned children are obviously also emotionally affected by the loss of parents due to HIV/AIDS associated diseases.

There are different kinds of responses that people go through after the loss of a love one. Bearing in mind that not all people go through these stages, Gibson et al (2002:114-115) have identified certain stages or kinds of feelings that people go through when they are facing grief. The first is *denial and Isolation* whereby the person finds it hard to accept the loss. They may act as if nothing has happened and keep saying that they do not believe that the loss has occurred. The second response is *anger.* They may feel angry with the dead person, or with themselves, or with God and with others. In other circumstances anger is morally justifiable, such as in situations where anger felt for instance by a survivor of sexual assault toward her assailant. The third stage is *bargaining.* The person at this stage tries hard to soften the blow by fantasizing that things could be different if they had done something. For example, people may find

themselves praying, trying to strike a bargain with God to bring the dead back. The fourth stage is *depression*. Now the person realizes that the loved-one is indeed gone, and becomes very sad, sometimes withdrawing from others. This emotional state is common to people dealing with difficult life circumstances. Depression is more likely when the circumstances involve significant loss. The last stage is *acceptance.* The person has now come to terms with the loss and life returns to normal to some degree. The above emotional effects have an impact on individual's behaviour. Hence change in behaviour occurs in individuals' lives. Often the pain of loss never really goes away but people tend to be able to deal with it over time.

Mourning is the only way to give due honour to loss. Psychology Today (2005) describes mourning "as the process by which people adapt to a loss." Factors, such as cultural customs, rituals, and society's rules for coping with loss, influence the process of mourning. Bereaved people may experience disturbance in concentration and lack of motivation, which makes it difficult to absorb new knowledge. Bereavement, according to Granot (2005:110), is the first step towards the acceptance of the new reality. Psychology today (2005) states that bereavement is a type of depression related to grief. It is the period after a loss, during which grief is experienced and mourning occurs. Bereavement is identified with four basic phases. But all the phases may not occur with every individual. These phases are the following:

- Numbness and shock are the responses to hearing the news of death. It lasts for a brief period and helps mourners to function through the funeral preparations and service.
- A feeling of separation comes when the sense of loss or missing the loved becomes a reality.
- Disorganisation is the period when the bereaved are distracted, have difficulty in concentrating and may feel restless.

- Reorganisation is when they have accepted that the loved one is gone and will not come back. Now is the time to adjust to life without the loved one. They have to reorganize themselves and focus to their future.

As a way of helping HIV/AIDS orphans as heads of households to separate from the one died, there is a need to redirect their emotional energy. Since some orphans have the responsibility of caring for siblings, they can begin to derive their emotional satisfaction from loving and being loved by the siblings as they learn to live without parents. As far as pastoral caregivers are concerned, it is true that individuals can never enter fully into the pain of another person, because the way individuals suffer is unique. But Campbell (1986:36) points out that by acknowledging our wounds and facing our own finitude, we can, in a small way, be healers of others.

4.2.1.2   Cognitive Development

Jeff LeRoux (in Matsumoto 1994:51) explains cognition as a general term that encompasses all mental processes that transform sensory input into knowledge. This process involves perception, rational, thinking and reasoning, language, memory, problem solving, decision-making and the like. Newman & Newman (1999:68) describe cognition as the process of organizing and making meaning of experience. Interpreting a statement, solving a problem, synthesizing, information, critically analysing a complex task, all are cognitive activities. Jean Piaget, the classic cognitive development theorist, suggests that changes in thinking reflect fundamental changes in the way people understand and organize knowledge (in Kail & Cavanaugh 1996:17). Therefore the grief process as described above is bound to affect the way in which people function cognitively.

 Cognitive development refers to changes in the process of thinking, learning, perceiving, understanding and recalling and is about how people confront new challenges and opportunities (Nicholas 2003:30). The earliest theory of cognitive development is that offered by Jean Piaget. His theory has been challenged,

criticised and expanded by for example Lev Vygotsky, and Jerome Bruner. Bruner is referred to as an intervention psychologist and focuses on "the child as thinker" (McIlveen & Gross 1997:39). The Vygotskyans (named after the Russian psychologist) see children as participants in an active process by which socially and culturally determined knowledge and understanding become individualized. Information-process theory view children as manipulators of symbols. As a way of promoting self-initiated interaction with the environment biological forces and experience are combined in order to produce the developmental change. Piaget's theory ties together maturation and experience on the one hand, and cognitive and social development on the other. People adjust their ways of thinking in response to new experiences. Most of the time young people abandon the old ways of thinking in favour of the new.

Paiget introduced four stages of cognitive development:

- the sensorimotor stage   from birth to two years
- the preoperational stage   two to seven years
- the concrete operational stage   seven to 11years
- the formal operational stage   11 years onwards.

The *sensorimotor stage* is when infants learn about the world primarily through their senses and discover things by sensing and doing. The infant engages only when the object appears. It if disappears and does not reappear he/she looses interest. Child development will progressively continue until the child is able to infer "invisible displacements", at which time the development of object permanence is complete. The next step is the emergence of fear of strangers. At eight or nine months they are able to combine schemes. Faces that cannot be assimilated into the schemas result in distress to infants. At the end of sensorimotor stage the infant develops a sense of self-recognition and language.

65

The preoperational stage is when children continue to use internal images, symbols, and language, which are important to their developing sense of self-awareness. Piaget identified some characteristic shortcomings in preschoolers' symbolic skills. The first one is egocentrism. Preoperational children think that other people see things as they do. Kail & Cavanaugh (1996:114) put it as follows: "Children typically believe that others see the world both literally and figuratively exactly as they do." According to Piaget, preoperational children are egocentric, which means that it is difficult for them to see the world from others' point of view (Kail & Cavanaugh 1996:114; cf McIlveen & Gross 1997:44). They do not appreciate it if other people differ from their ideas, convictions and emotions. This is illustrated by means of the "Swiss mountain scene" test mentioned in Kail & Cavanaugh (1996:115) and McIlveen & Gross (1997:44). Preoperational children were asked to choose the picture that corresponds with other persons' views of the mountains, but they chose a picture, which matched their own view of the model. Only the children aged seven or eight (concrete operational stage) managed to choose the picture that corresponds with other person's views. Hence, Paiget (in McIllveen & Gross 1997:44) argues that preoperational children are bound by the "egocentric illusion." This means they take the world as it is because they fail to understand that what they see is relevant to their own position.

Preoperational children may credit inanimate objects with life and mental processes, for example to them, if sheep and dogs both have four legs, then sheep must be dogs. Preoperational children may believe that objects like sun is alive and thinks and feels the same as people. They also have problem in reversing thinking, especially in logical and mathematical operations.

The *concrete operational stage* is where children are capable of thinking logically in the presence of an actual and observable object. They have the ability to conserve and to relate to the phenomena of reversibility and classification. The concrete operational stage shows a significant decline in egocentrism. According

to McIlveen & Gross (1997:45), the growing relativism of the child's viewpoint is the onset of seriation-learning, that is how to order things, and reciprocity of relationships such as knowing that adding one to three produces the same amount as taking one from five. However, their thinking is limited to the tangible and real, to the here and now (Kail & Cavanaugh 1996:181). James Byrnes (in Adams & Berionsky 2003:227) argues, "As children negotiate their way through the adolescent period they confront many challenges and opportunities. These challenges and opportunities may lead to improvements in their social, emotional and intellectual competencies." However, when children lack access to important resources then progress is impeded.

The *formal operational stage* extends from roughly age 11 into adulthood. Adolescents at this stage are able to think hypothetically and reason abstractly, as compared to concrete operational youngsters. According to Matsumoto (1994:103) individuals develop the ability to think logically about abstract concepts such as peace, freedom and justice. With regard to problem solving strategies adolescents take a very different approach from concrete operational children. Adolescents and adults do more reasoning and scientific thinking tasks, when they are motivated to use their skills.

Piaget and his follower's theories of cognitive development mostly focused on Western culture, which tends to be individualistic. In the African context parents, the extended family, and the community play a major role in the development of children. It becomes a problem when children grow up without the guidance of an older person. They do what they think is right, but are not always able to distinguish between right and wrong. Some times they will get themselves into trouble because of their choices. Vygotsky (in McIlveen & Gross 1994:55) argues that a child's cognitive development cannot occur in a social vacuum. As social beings we are capable of interacting with others, but infants can little for themselves, either practically or intellectually.

4.2.2 Social Factors

Loughry & Eyber (2004:1-2) point to "the influence of social factors on an individual's mind or behaviour and to the interrelation of behavioural and social factors; also pertaining to the mind and development." This shows that social factors have an influence on human thoughts and behaviour and on people's world. In addition Togni (1996:114) states that all human beings learn their culture through a process of socialization and interaction with other individuals in society and also with the physical environment. This statement shares the same sentiments with Vygotsky (in McIlveen & Gross 1997:39) who views "children as participants in an interactive process by which socially and culturally determined knowledge and understanding become individualised". On the same note Togni (1996:115-116) sees the learning of language as one of the important aspects of culture. Language plays a major role in the cultural development of a child, because through language ideas, norms, and values and other facets of culture are transmitted and communicated. Social factors refer to the capacity to form relationship with other people and to learn and follow culturally appropriate social codes.

Children in African societies are under a strict parental control until they reach puberty when they are put through certain rituals of initiation. During this stage they are able to learn the norms, values and moral codes of a traditional society. The family is seen as the first of one's social networks. This study is interested in social change when children who are supposed to be under the care and guidance of adult people are now on their own. Togni (1996:23) is of the opinion that family is more readily amenable to analysis than any other social networks. When I refer to family in the context of HIV/AIDS orphans as heads of households I mean nuclear or extended families.

Family plays a very important role in caring and taking responsibility for orphaned children. It also plays a vital role in providing affection and companionship for children and adults too. Black families in South Africa have very different

experience depending on whether their setting is urban or rural. In the rural areas extended families often still have the human understanding that they have a responsibility to take care of orphaned children within the family, no matter what happened. Family friends can also play a major role in providing supportive networks for HIV/AIDS orphans as heads of households. The other potential social support networks are peers and communities.

The positive peer networks can play an important protective role as they give a sense of social acceptance, identity and values. These networks are particularly important when other protective factors are not available. When primary structures (families and extended families) fail, the alternative is that communities have to take over and ensure that these children are protected from physical, emotional, psychological, social and sexual abuse. Uys & Cameron (2003:181) state that members of the community are in the best position to know which households are severely affected and the type of help that is appropriate. Mostly communities know who is dying, who has died, whom relatives have taken in, who lives alone, and who has enough to eat. They are able to delegate responsibility to people in the neighbourhood to keep an eye on child headed households. Schools play a significant role in the socio-emotional development of children, but unfortunately not much attention has been given to ways of enhancing their ability to provide support to children in general and specifically to children from families affected by AIDS. HIV/AIDS orphans leave school because of peer pressure, scorn, isolation, discrimination and stigmatisation, while by the same token positive networks could play an important protective role. They could provide a sense of social acceptance, identity, and values. Stigmatisation and rejection by society exacerbate the already huge problems of these children as they attempt to survive without social support. Discrimination against the infected and affected results in children being rejected by their peer groups. When infected children show signs of skin infection they are asked to leave school. This is another lost opportunity for them to live with and adapt themselves to society.

Role models beyond the family can be an important protective factor. Teachers and career counsellors can play important supportive role.

Religious communities also have a major role to play in the nurturing of HIV/AIDS orphans as heads of households. Gerkin (1997:171) uses the example of Cedric who was supported by church leaders and teachers, which helped him to turn his life into a positive direction. All churches should embark on building a supportive environment where HIV/AIDS orphans and other vulnerable children will feel accepted and supported. Some churches have already taken action against the stigmatisation of HIV/AIDS. Churches should become the voice of the voiceless, and help to safeguard the rights of children affected and orphaned by the HIV/AIDS pandemic. Churches should also protect the human rights of people living with HIV/AIDS nationally and internationally. By witnessing to the gospel of reconciliation churches can help to reconcile families in the context of HIV/AIDS. It has become clear in this study that HIV/AIDSS orphans as heads of households experience psychological trauma and some of them also become victim to physical, emotional and sexual abuse. Churches as faith community are called to be the healing community. Healing in this case could start where humans denounce stigma associated with HIV/AIDS and pronounce love, care and support.

WCC Study Documents (1997:77) emphasises that the experience of love, acceptance, and support within a community where God's love is made manifest, can be a powerful healing force. The church should not follow or take part in the exclusion, stigmatisation, and judgement and blaming of people on the basis of their behaviour. By creating an atmosphere whereby HIV/AIDS orphans as heads of households can express their feelings, pain, and suffering as human beings, a safe environment for healing can become available to the children.

4.2.3 Spiritual Growth and Development

Spiritual development can take place at any age, although it tends to assume adult or adolescents abilities (Meier et al 1991:255). Christians often describe spiritual development as conversion or new birth. It starts when individuals become aware of the existence of a Supreme Being, but have no real knowledge yet of the gospel. Meier et al (1991:256) put it as follows: "Development begins with salvation or spiritual birth." 2 Corinthians 5:17 is the testimony of this new birth: "So if anyone is in Christ, there is a new creation: everything old has passed away …" Thus because of their immaturity those who have been "newly born" will need guidance in order to grow in discipleship. Meier et al call this stage "spiritual childhood" after which follows adolescence, a stage marked by uncertainty and conflict. Along this way of faith there are loops in the progression. Lack of intimacy with God is mostly caused by emotional pain. But as people develop a sense of identity and realise that God loves them unconditionally, they will be able to establish a strong self-identity. Even the weak are able to gain strength.

Before infants are baptised their parents have to promise that they will guide young children in their spiritual development, teach them, train them and bring them up in the instruction of the Lord. But some parents, especially fathers, often fall short. They become wrapped up in their own world and neglect their highest calling which is the spiritual development of their children. This spiritual development does not start when people are old or near death, as some young people who resist being attached to any religious institution, tend to think. They say they are still young and faith is for elderly people. The opposite is true. Spiritual development can start from infancy. Through parental faith infants will sense the overall atmosphere in the home and begin to respond to parental behaviour and attitudes. Parents may play a vital role in teaching their children to say a memorised prayer from young age. Children, who grow up in a loving, secure, and accepting environment during their early years can develop a basic trust, which enables them to have meaningful faith in God later in their lives. The

71

practical theologian whose work focuses on faith development, James Fowler (1987:58), points out that faith begins with a kind of pre-language disposition of trust and loyalty toward the environment. This is described in Erikson's theory as the tension between basic trust and basic mistrust. If the "culture of mothering" is disrupted at this stage, the child is put at under serious emotional risk. Biblical stories of Jesus and of children have a great deal of meaning to pre-school children. Parents should help children to distinguish between a fairy story and a Biblical story, which has profound meaning for their lives. As families conduct their devotions at homes it is the time in which they share Christ with one another. Children in elementary school (about age 11) are able to understand some abstract matters of the Christian faith. Churches, who truly put their faith and the Biblical teachings into practice, can show love and support for both their members and the broader community. In this regard this study is especially concerned with HIV/AIDS orphans as heads of households who undergo many traumatic experiences and receive little if any support. In the absence of parents and the support of family, I believe that Christian communities can play a vital role in loving and supporting these children and guiding, training and teaching them in the knowledge and fear of God.

In search for their identity, teenagers find it important to integrate faith in their life system. This helps them to find some positive answers to their many questions. In the faith community they can meet some positive people who can show them positive ways of coping with life. Young men and women in their teens and early twenties feel they are independent of their parents. They can make their own choices. If the foundation had already been laid before they reached this stage, teenagers will remember the teaching they received at a younger age. "Train children in the right way and when old they will not stray" (Proverbs 22:6).

4.2.4 Summary

In this chapter the contribution of psychosocial theory for the understanding of the cultural growth of individuals was examined. Through intimacy with parents

children become aware of when parents are physically and psychologically available or unavailable. This becomes problematic when people such as adolescents who, because of their inexperience and immaturity, cannot be fully available to the little ones care and of other children. Parents are playing a major role in promoting the psychological growth of their children.

Adolescents go through a difficult life stage where they are prone to being depressed. The feeling that friends do not understand them, pressure from parents, the confusing search for identity, which is part of this stage, causes depression from these adolescents. It is exacerbated when they experience the loss of parents and prematurely take up the responsibility of heading a household and caring for siblings. Poverty has proved to be a major obstacle to rewarding experiences and interactions of HIV/AIDS orphans with other teenagers, peers, community members, and extended family.

CHAPTER 5
FIELD RESEARCH

5.1   Introduction

This chapter reports on the fieldwork I have undertaken in the Bophelong area among HIV/AIDS orphans who function as heads of households and children who have become orphans due to circumstances other than HIV/AIDS. The reason for choosing this area is that it is a recent development with new RDP houses and informal settlements for people coming from nearby farms and other surrounding areas. As I have mentioned in chapter one, it was not difficult to find HIV/AIDS orphans who function as heads of households, because of well-organised structures such as Community Based Care Organisation (CBCO) and Home Based Care Organisation (HBCO) in the area. I had no previous contacts in the area. I found name and address of Mrs Diphare and the organization she was leading as a coordinator at Bophelong in the list of organisations, which deal with orphans and child, headed households in the Gauteng Province under Social Development. We met and she gave me the history of the organisation and told me about the children they are caring for. When she passed away early in 2005 other arrangements had to be made with the new leaders of the organization. In the end I manage to receive permission to conduct research at Bophelong. This was a suitable area for my field research. Frankfort-Nachmias & Nachmias (1992:273) define field research as "the study of people acting in the natural courses of their daily lives. However the fieldworker is one who ventures into the worlds of others in order to learn firsthand about how they live, how they talk, and behave and what captivates and distresses them." Fieldwork calls for empathy and understanding of the subjective meanings of people studied.

The theoretical framework that informed the fieldwork undertaken here was that of a qualitative methodology. This theory was discussed in some detail in the introduction. Initially, I visited eight households with the intention of procuring a

suitable sample. Because it is not possible to study all the eligible subjects, a representative sample of the population was selected. Five of these households were selected since they were the only ones that fitted the requirements mentioned earlier. The age of the heads of the households ranged between 16 and 18 years. There were two male-headed households and one female-headed household. The orphan heads of households whose parents did not die of AIDS were 13 and 15, one female and one male. The sample is "a subset of the population" (Bless & Hidgson Smith 1995:88). Data collection was conducted by means of semi-structured interviews and observation.

The following is a report on the analysis of the social, psychological, emotional, educational, developmental and spiritual effects of HIV/AIDS on orphans who function as heads of households.

5.2 Research Process

Interviews and observation were adopted as the instruments of research (see sections 1.6.3.1 and 1.6.3.2 of this study). These methods were used interchangeably, not separately.

5.2.1 Interviews

The main purpose of using interviews in this research was to discover the reality of the experiences of HIV/AIDS orphans as heads of households and of their siblings and wanting to become part of the circumstances in which they are living. In this chapter I will sometimes use "house" instead of household. This study also attempts to highlight the added difficulties in the lives of HIV/AIDS orphans as heads of the households as compared to children who were orphaned by circumstances other than AIDS, for example accidents and murder. The interviews were open-ended interviews and the participants were asked the same questions. As mentioned by Denzin & Lincoln (2000:649) the list of issues for investigation was drawn up prior to the interview. Secondly, since the interviews were semi-structured. All interviews were conducted in the vernacular while

English words and phrases frequently featured. During the interviews a tape recorder was used and notes were taken of the responses of the participants during the course of the interview. Translation of the interviews into English was done soon enough after the interview. During interviews the interviewer could become part of the group and was therefore able to observe and listen to the stories and identify troubling issues.

5.3   Household No.1 – Participant: Marry

- **Family Background**

Marry comes from a family of six children. She is 18 years old and the youngest is a boy of 5. The family lives in a three-roomed RDP house that their parents left to them. Marry and her siblings lost their father in 2002 because of prolonged severe bout of pneumonia and their mother died in April 2005 because of heart disease. The eldest sister is married, has her own house, and is not working. Her husband is not popular among the girls because he is abusive. Even if they had nothing in the house they would not ask him for anything because when he is drunk he swears at them for being poor and always having nothing. The third sister, Dolly, is 16 years old and has a two-month old baby. She is doing grade 10. They receive support from the elder brother of their father who visits them at least twice per month. Their grandfather has his own family to support, so he cannot help. Relatives came for the funeral, after which they disappeared. The children loved their mother very much. She was open about aspects of life and could talk to them about anything. She taught them to unite as a family. They are associated with the Zion Christian Church (ZCC) whose members visit them every month and are spiritually supportive.

- **Traumatic Experience**

Marry stated that she and her siblings do not have money to purchase food and electricity. As the oldest person in the household she is responsible for food and electricity. They rely on their grandfather and their sister who sometimes buy

76

them food and electricity. The neighbours are scornful because they have nothing. They chase her siblings away when its time to eat. The neighbours even beat and shout at her siblings because they have no one to stand up for them. Sometimes the neighbours say hurtful things.

According to Marry, they have a problem at school because some teachers do not understand that they have no parents even though they did report it. It becomes even more traumatic when there is a parents' meeting at school. While their parents used to represent other children, not one is willing to represent these orphans. One of the siblings commented that her principal would not listen them when they told him that they have no parents. He told them to bring a guardian. The difficult part is that relatives were not able to help. At times they have to go to school hungry. Dolly says: "It is painful to go to school hungry, because you loose concentration and its embarrassing to be with people who have lunch, school uniforms, and shoes whereas you have nothing. Sometimes at school you think about the life you are living at home and don't concentrate at studies." Hence some students had to repeat their classes.

The participants are angry with their aunts who make empty promises in front of the siblings. They say they are going to buy them clothes and food, but then they vanish, never to be seen again. The younger children would nag at the older ones about the clothes and food that have been promised. They want the older children to follow up and ask the aunts about their promise. The participants say they could not apply for grants for the younger siblings because their grandfather had promised to do it for them. The participants are not happy about the situation, but they cannot say or do anything about it because their grandfather will be angry and cut off the little money he is giving them. After the application it takes three months before they can get the money. If their grandfather cuts them off and they have to wait for the grant money, who is going to provide for them in the meantime? Therefore they have decided to wait for him to do something about it.

According to Marry, her mother had been ill from a young age. She suffered from heart disease. After the death of her father the mother who had always been so open about every aspect of life, became reserved and worried about her health. The death of their parents left a void in these children's lives. They have had to assume adult roles. The participant and her siblings often feel helpless and afraid and sometimes they cry when things do not go well. The participant and her siblings are living in fear of male visitors who sometimes want to enter their house by force at nights. They do not know whether these men are from the neighbourhood or from other areas. Although Marry and Dolly are old enough for ID's they both do not have them, though they have all the other necessary documents. They loved both their parents, but were especially close to their mother. Her instruction has remained in their minds, hearts and souls. I could see that the house is well kept, though the furniture is sparse.

- **Education**

Marry feels that teachers lack compassion and thoughtfulness. If they should assist the children who do not have parents to support them, the children will feel loved and be motivated to go to school everyday. Marry does not like other school children to know that they are orphans because she does not like to be pitied. She wants to be treated like any other child. She and her sister would like for schools bursaries to be made available to all vulnerable children. Some schools have feeding scheme projects. If this could be made available to all schools it would especially help children from orphaned households.

- **Future Expectations**

The participant felt so adamant about the future but she hopes that when she finishes grade 12 things will change. She could get a job and continue with her studies because she wants to be fashion designer. On the other hand she would like to help her siblings to continue with schooling until they reach a stage where they could help in the house.

5.4 Household No 2 – Participant: Tebogo

- **Family Background**

Tebogo is 18 years old and is the head of the household. Their household consists of five boys, the youngest of who is 9 years old. Their father left them when they were very young and the mother fell in love with another man. After the death of their mother in June 2005 they were left to fend themselves. Their maternal grandmother and uncle are supportive. They visit them regularly and sometimes bring food. From paternal side neither the father himself or any of his relatives bother about the children. Tebogo is not in school. He left school at grade 11 when his mother became ill. The reason for his leaving school is because he wanted to take care of his mother. He could also not concentrate at school because he worried too much about his mother. He saw his mother losing weight and it was evident that her health was deteriorating rapidly. Tebogo decided to stay with her so that he could be there for her when she died. He did everything for her because no one came to help, not even her sisters. They only attended the funeral, after which they disappeared.

- **Traumatic Experience**

As the head of the household the participant has to make sure that there is food in the house. He sells fruit and vegetables in order to have money to buy electricity, food and clothes. But his brothers are not supportive. Instead of helping him they steal from the house. The second brother is David who is 16 years old. He is involved in drug abuse. All windows of the house are broken. David did that. He keeps bad company, though he still attends school. At times he would come and take food from the house to eat with his friend with whom he is staying. The 14-year-old brother steals from Tebogo and also stays with friends until midnight. The loss of his mother has left the participant with the adult role. The image of his sick mother does not fade easily. There are times that he wishes he could just sit by himself without being disturbed by anyone. When he

79

talks about his mother's illness he has a pained expression on his face. He is relieved that she has died, because she suffered too much. She had to go to hospital often where many tests, including blood tests, were done. When he mentioned the blood tests there was a long silence and tears ran down his face. Though he could not say what exactly the cause of his mother's illness and death was, it was clear that he knew it was something exceedingly painful.

- **Education**

The participant believes that it will not be easy for him to go to school at present. He would first try and help his siblings. Once they have succeeded he will go back to school, even though it may be rather late for him to do so. In the parents' meeting it was reported that, starting from 2006, school fees for the secondary level would be scrapped. This will give pupils who have nothing, a chance to reach the secondary level. The problem was the primary school where school fees were still payable. Tebogo monitors his sibling's education. He visits the school to enquire after their progress. David has a problem with economics, but he manages with the other subjects. Everyday Tebogo checks their books in order to make sure that they were at school. He finds the teachers and other students supportive.

- **Future Expectations**

The participant is positive about the future although he still has to finish school. His priority at present is to see his brothers succeed in their schooling and then he can go back to school. His future plans are to have his own house and leave his bothers in the present house where ritual ceremonies would be conducted. Although poverty seems to be a stumbling block, he is positive about life. The small business he is involved with, has taught him ways of solving problems.

5.5   Household No 3 – Participant: Lucky

- **Family Background**

Lucky is a 16 years old shy and soft-spoken young man. His father and mother died in 1998 and 2003 respectively. His father was shot and the mother had been sick for a long time. I asked him, what was wrong with your mother? He took a deep breath after some seconds he said, "she had suffered from pneumonia". The parents left him a four-roomed house. He is still at school doing grade 10. The parents had two children, a girl who also died in 2004 and the son named Lucky. His extended family on the paternal side live in Durban and his aunt lives in Bloemfontein. She only comes to visit during the December holidays. Lucky has been living alone thus far. The family in Durban does not visit at all. Though he does visit them, they are not supportive at all. Sometimes his aunt would send him some money. Lucky has created a new family of friends who are supportive.

- Traumatic experience

After the death of his parents it was not easy. Though his father had left them some money most of it was used for his mother's illness. He finds himself living alone, painful and stressful and even thought of suicide. Everyday he misses his parents. He sometimes sees images of his mother in those late stages of her life. When she died he cried in order to remove the pain.

When he left the house on the day of her death he could see that his mother was very ill. Had it not been holiday time he would have nursed his mother. Fortunately his aunt was there for holidays and she took care of her sister. The paternal aunts however discriminated against his family and isolated them. At the funeral they started arguing and wanted the house. They thought Lucky should go and live in Durban and look after the cows. The maternal aunt refused and saw to it that this young man should remain in his parents' house.

81

- Education

After the death of his sister in 2004, Lucky could not take it anymore. To him going to school was a waste of time because he was not able to concentrate at all. He dropped out of school in 2004 and started afresh in 2005. Now things are better and he is doing well in his school. At school nobody except his class teacher and close friends knows that he is an orphan who lives alone. At school they have organized a sort of support group for children who are the heads of households. In the group they share their problems especially poverty and financial difficulties. Some members of the group are HIV/AIDS infected. They do not tell the other students about it because they would gossip about them. Secondly, when students know that there is no adult in a certain house they tend to occupy the house and do wrong things like stealing, invite girlfriends to the house and use it as storage place for stolen goods. At the moment Lucky is not associated with any religious institution.

- Future Expectations

After finishing grade 12 Lucky would like to be a journalist. He likes to read magazines and books. In his spare time he writes stories about his life and friends. He has also written a biography about his family, which he would like to publish some day. He would like to find a job in order to erect a tombstone for his parents and sister. Lucky does not particularly appreciate other family members, but he would like to have an older person living with him. He wants to be treated like any other child, with parental guidance, discipline and care.

At the end of the conversation he was thankful for this type of conversation. He commented that neighbours just see you coming and going but no one bothers to ask how you are coping. How did you sleep? Is there anything we can help you with? As I observed the situation one would not think there were no parents in the house because it is well kept and clean.

The above participants are from households affected by HIV/AIDS. They are now the heads of the households. Lucky's situation is that of the father having been murdered and the mother having died of an HIV/AIDS related disease. Although some children still have father he has vanish without trace which leaves these young men and women heads of households. The following section is about orphans whose situation is not HIV/AIDS related. They are also not heads of households.

5.6   Household No 4 – Participant: Zolile

- Family background

Zolile is 15 years old, in grade 7 and the youngest of the family. His name means "the calm one". His elder brother is working and the sister has left home and is involved in sex work. Their father abandoned them and left them with their mother. They stayed in a three-roomed RDP house with a shack at the back for the older brother. In 2003 their mother and their youngest sister were instantly killed in a hit and run accident. The children were left with grandmother to look after them. However, the grandmother became ill and then there was no one to care for them. It was decided that the maternal aunt should come and take care of the children. After grandmother's death the aunt decided to come and live in the house.

- Traumatic Experience

The participant often watched his aunt fighting with his brother but he could not figure out what the problem was. One day the aunt told them to move out of the house because she wanted to let the house to other people. There was a great fight but in the end they had to move out of the house. The worst part was that they had to go and live in the brother's wife's home. That is a sign of weakness in an African context. Although the house is registered in Zolile's name, he was turned out of his own house because of a greedy aunt. He is now struggling to make ends meet. At school he owes school-fees, which his brother promised to

pay at the end of the November. His living conditions are not healthy. He is staying in an overcrowded two-roomed house. Although he is happy because he has a roof over his head, he is suffering because a lack of money to take to school. His brother earns only R200 per week working in gardens. With that he has to support the whole family. It is traumatic for Zolile to know that, though the house belongs to him, the aunt is making money for herself while he does not get anything. He does not have sufficient clothes. Knowing that his father is alive but that he does not want to take any responsibility for his actions fills Zolile with hatred for him.

- Education

The report from school shows that Zolile is a brilliant student who only needs family support. The teachers at school are quite satisfied with his work although they notice that most of the time he would sit alone and in deep thought. Schools should develop an opportunity for students to talk about what bothers them. At tertiary level there are student counsellors. This, I believe, should be the case at the lower levels also. African schools still lack this facility.

- Future Expectations

The participant is worried about the future because he does not know how long his brother would manage with the little he is earning. His wish is to be a policeman or lawyer one day in order to protect people like him against evil people. Currently he is living with the family because he is at school. The following year he will have to change school because his brother has received informal housing in another area. If he should continue at his old school, transport will be a problem since there is no money for that.

The participant is part of the statistics of orphans chased out of their houses by greedy extended family members. This leaves him with anger against the family, which might cause him to do something wrong when he is old enough. He should be rescued before it is too late. Had the father not left them and had he taken

responsibility for them, they would not been in this mess. This makes Zolile angry as well. He is also angry with the person who has taken the lives of his mother and sister who was too cowardly to take responsibility for what he had done. He feels that his life is messed up at the moment, but maybe he will see it in a different light later.

5.7   Household No 5 – Participant: Maria

- Family Background

Maria is thirteen years old and in grade 5. She has a sister who is sixteen and stays with her boyfriend in an informal settlement close by. She and the immediate family live in a shack (informal settlement) extension 11 in Bophelong. Her father murdered her mother but he is still a free man. After a problem between the two families the maternal grandmother had to take the children to live with them. The elder daughter decided to leave and start her own family. She does visit them but she would not tell them exactly where she is living. The paternal family does not support the children in any way.

- Traumatic Experiences

The death of her mother has left a deep dark hole in her life. The children were present when the father murdered the mother. It started as an argument, which led to the father stabbing the mother a number of times in the chest. This left Maria with emotional pain, which is disturbing to her. The grandmother said that they have visited a psychologist who helped them cope with the situation. When Maria comes from school the dishes are waiting. The other children sit on the couch and watch and no one bothers to help.

- Education

Maria is doing well at school. She spends most of her time at school doing homework studying. Although she sometimes goes to school hungry she likes going to school. Her class teacher is supportive. She took it as her responsibility

to make sure that Maria has something to eat during lunch break, because the child has not mother to take care of her.

- Future Expectations

Maria is unsure about the future. She is concerned about what is going to happen after the death of her grandmother. She would like to be with her sister so that they can be a family like before.

The study has shown that both HIV/AIDS orphans as heads of households and children who have been orphaned by other circumstances undergo traumatic experiences. Some of these experiences challenge their psychological, cognitive, emotional, social and spiritual development. There does not seem to be too much of a difference between the experiences of the two groups of orphans, although orphans who do not have to cope with the HIV/AIDS stigma have the opportunity of family support more often. However, they are treated as secondary citizens.

5.8   Summary

This study has shown that orphans heading households are stressed on account of the situation in which they find themselves. They have to find food for siblings and make sure that there is electricity. They sorely need adult support, but their families seem to neglect them. Neighbours do not care what is going on in the orphans' households. These children fear the future. They worry about family members and others who come to steal from them and cheat them out of their property. These people steal their groceries, blankets and clothes to give to their own children and leave the orphaned children with nothing.

Emotionally the orphans mourn for their parents, wishing that they were still alive. The strength they got from the parents is what keeps them going. The changes in behaviour of the younger siblings are signs of distress. Older children

also show behavioural problems such as stealing from the house, using drugs, engaged in an unprotected sex, which could result in having a baby or contracting HIV.

Those children affiliated with religious institutions have all the emotional and spiritual support they need. The HCBC helped to minimize the trauma of having lost their parents by visiting them regularly checking how they live. They also help them buy uniforms and check if they have the necessary documents. They make sure that the children benefit from the food parcels supplied by the Department of Welfare and Development. The HCBC makes sure that their rights are protected all the times.

CHAPTER 6
PASTORAL CARE AND COUNSELING

6.1   Introduction

In this chapter the focus is on the role of pastoral care and counselling as a way of empowering HIV/AIDS orphans as heads of households. It has become clear that HIV/AIDS orphans undergo traumatic experiences: the trauma of caring for parents dying of a debilitating disease like HIV/AIDS, of losing parent(s), of having to looking after siblings at an age when they are not yet prepared for the task, of being isolated or exploited by the extended family, of being poor, lacking in socio-economic support, of having to leave school because of the scorn and rejection of peers and some teachers, and of having to look for a job at a young age in order to support their family.

These orphans join the ranks of the socially marginalized and street children. Those who become street children are more vulnerable to police harassment, frequent physical and sexual molestation, and harassment by older and more powerful street dwellers such as homeless adults, prostitutes and gangs. The aim of this chapter is to answer the question: What is the challenge to pastoral care in this context? I will start with some views on pastoral care.

Pastoral care is a way to enable people and communities to find meaning and make connections between their life experiences and the God who is concerned about the whole creation. So says Grossoehme (1999:14) who further describes pastoral care as "God's love mediated", by the pastoral caregivers to people who are hurting. Similarly, Emmanuel Lartey (2003:61) describes pastoral care as: "to assist men and women and boys and girls to live as disciples of Jesus." The aim is to encourage people to make sense of their own experience. In the context of HIV/AIDS orphans as heads of households who are subject to one traumatising experience after the other, pastoral care can play a vital role in empowering them

88

for survival. HIV/AIDS orphans who function as heads of households at an early age experience the constant violation of their rights, which is accompanied by physical, emotional, psychological and spiritual abuse. All of this is traumatic to the children. The faith community can and should be involved in trying to help and support these children, as well as becoming advocates for justice. The WCC Study Document (1997:77) states that churches can make an effective healing witness towards those affected by HIV/AIDS epidemic of which the children are certainly the most vulnerable. This document adds that the experience of love, acceptance, and support within a community where God's love is made manifest, can be a powerful healing force.

If the faith community responds to HIV/AIDS orphans as heads of households by ministering to them and learning from their suffering, then a difference can be made to their lives. Charles Gerkin's (1997:11) view on pastoral care is that it is the arena within which the pastor is privileged to be with people where they live and breathe, succeed, fail to relate intimately, and experience alienation. According to the Gospel of John (16:12) Jesus said to his disciples: "This is my commandment, that you love one another as I have loved you". With love goes care. When you love something you will protect it, as David once said to Saul: "Your servant used to keep sheep for his father; and whenever the lion or bear carries off a lamb I go after it, attack it and rescue the lamb…" (1 Sam 17:34 NRSV).

For pastoral care givers called into this caring ministry the focus should especially be on those who are most vulnerable. Stairs (2000:10) raises the question: "What will make pastoral care truly and not merely any form of care?" Understanding the origin of pastoral care will help to answer the question. Pastoral care is associated with the rural shepherding role whereby the shepherd spends most of his time looking after the sheep. The shepherd always carries oil to pour on the wounds of the wounded sheep. This image of the caring shepherd was applied to the pastor as the shepherd of the flock of Christ. The origin of this

89

idea is the Biblical text where Jesus calls himself a "good shepherd, who knows his sheep and is known by his sheep" (John 10:11, 14). According to Gerkin (1997:82), to be a good pastor is "to seek to understand the deepest longings, the secret sins and fears of the people so that the healing unction of our understanding may communicate that as pastoral caregivers and the God we serve care deeply and intimately for them". As HIV/AIDS orphans as heads of households go through traumatic experiences, they find themselves bruised and broken in many ways. They find themselves in need of physical, emotional, and spiritual restoration (Lartey 2003:62). Pastoral caregivers should assess the care-seekers' situation based on the stories they tell of their lives.

On the other hand Gerkin (1997:84) states that care has to do with a certain ordering of human actions and relationships. Uys & Cameron (2003:4) point out that Africans used to have an effective home care system before HIV/AIDS came on the scene. Ordained pastors did not necessarily practise this kind of care, the people in the community were taking care of the sick and also acting as midwives. It would not have been too difficult for health departments and hospitals to train people for home based care for people with HIV/AIDS. Home based care entails the provision of needed health care by a primary caregiver to a patient or family at home, often supported by community caregivers. Home based care should play a major role in the caring of HIV/AIDS infected and affected people, for example it could enable people living with HIV/AIDS (PLHA) to feel less isolated from family and friends, it will limit problems such as transport, daily visits to the hospital and other costs, and after the death of the parents home and community based care will continue to help the HIV/AIDS orphans. The HCBC is taking on the task of organizing and receiving social grants for orphans, helping orphans register and apply for approved identity documents. They make sure that orphaned children are attending school and organising financial help and uniforms for them. The HCBC does home visits, gives counselling and psychological and emotional support (Uys & Cameron 2003:7). It is important to the HCBC that their personnel receive proper training in

order to provide a high standard of care. The focus of pastoral care in this situation should be on the empowerment of those in need. The fact that their lives are so difficult does mean that they are weak. Through pastoral care their strengths can be recognised and on those strengths they can be helped to build new   lives.

Empowerment is about building relationships. Relationship, according to Campbell (1986:37), does not depend primarily upon the acquisition of knowledge or the development of skills. It depends upon a caring attitude towards others, which comes from one's own experience of pain, fear and loss and the ability to overcome it. Pastoral caregivers who work with an empowerment model seek to assist in the conscientization of the oppressed and marginalized through enabling them to ask questions about their life situations. In pastoral care relationships are formed based on caring attitudes. Relational skills are then used to assist people to explore, clarify and change unwanted thoughts feelings and behaviour.

6.2   Doing Pastoral Care with Children

To the healing, sustaining, guiding (see Hiltner 1949:89-171) and reconciling tasks of pastoral care (Lartey 2003:62-68), Clinebell (1979:17-19) also add nurturing. According to Campbell (1986:23), pastoral care means "soul care" by a wise and fatherly/motherly figure whose superior spiritual insight and moral rectitude equip him/her to lead the flock to safety. Pastoral care is a relationship founded upon the integrity of the individual. It is part of the human condition that human beings find themselves broken and bruised from time to time. This applies especially to HIV/AIDS orphans. The loss of parents is an emotional trauma, which is especially difficult to deal with in pastoral care. The loss of parents brings fears to the affected children. Because of these fears these children are asking questions that are not easy to answer. In order to be able to find a solution to these fears, it is helpful to first understand the basis of fear. Some fears are not voiced explicitly. However, Grossoehme (1999:44) argues that having an

understanding of the more primal fear underneath the worlds and emotions helps shape and influence the practical aspects of pastoral care. When parents are sick the fears of the children are: "What is going to happen if my mother or father dies? Who is going to take care of us?" These fears are readily articulated. What is not spoken about, are guilt feelings. Children often feel they have failed their parents for not being there when the parent(s) needed them.

Grossoehme (1999:50) states that guilt is a common feeling that anyone who provides pastoral care to children and youth will encounter. After the death of the parent or loved one the child feels guilty for not having been sufficiently available to the parent of they feel that they should have been able to have done something to stop what had happened. Sometimes these guilt feelings arise because their actions have violated their own ideas about what is right or wrong. Children and youth commonly experience inappropriate guilt, which means that they feel guilty about things they were not responsible for, or which was beyond their control. Children may feel responsible for parents' divorce or disease, for example.

6.3   Challenge to Pastoral Care

For centuries in the African context, the extended family system has met the basic needs of children and provided a protective social environment in which they could grow and develop (Uys & Cameron 2003:176). This is not the case any longer. The extended family, which used to function as a social support network for orphaned children, not longer does this. At a time when the extended family is needed as a support system for HIV/AIDS orphans as heads of households, the stigma associated with HIV/AIDS affects their willingness to care and support HIV/AIDS orphans. Their parents' health condition causes them to be stigmatised and this stigma continues even after the death of the parents. Extended families and communities treat the orphans with scorn and rejection. HIV/AIDS orphans are at risk of being sexually abused, marrying at a younger age in order to find security, which sometimes in turn results in continued

physical abuse. They are also often nutritionally deprived. Uys & Cameron (2003:177) mention the following problems encountered by HIV/AIDS orphans:

- poverty;
- lack of supervision and care;
- hunger;
- lack of adequate medical care;
- psychological problems;
- disruption of normal childhood and adolescence;
- poor housing;
- child labour.

These factors provide a challenge to pastoral care, because all of these needs require immediate attention. Churches and community should provide a climate of love. Pastoral care is also about inquiring about and helping people to consider the morality of their actions (Gerkin 1997:84). Dealing with stigmatisation is a great challenge. The gospel message is about the inclusion, not the exclusion of the marginalized and the needy. The fact that stigmatisation also has the effect that needy people are not cared for, should be addressed by the church. This too very much goes against the gospel. When pastoral care is indeed an illustration of the love of God, the only way is to break through the problem of stigmatisation and to practise an ethics of love.

Churches should find creative ways of building a supportive environment in which HIV/AIDS orphans who function as heads of households will feel accepted and supported. They are the victims of the situation and have certainly done nothing wrong. The mission of the church is to be the voice of the voiceless and to help to safeguard the rights of children affected and orphaned by the HIV/AIDS pandemic. Churches should protect the human rights of people living with HIV/AIDS by creating national and international mechanisms. Dealing with a community that has experienced psychological trauma is also challenging on a

pastoral level. Campbell (1986:41) suggests that as pastoral caregivers we should acknowledge our weaknesses and find God's healing force, which will strengthen us to become wounded healers. The goal of pastoral care and counselling on the individual level is to help HIV/AIDS orphans to come into terms with their situation and to help them develop coping strategies so that they can deal with their wounds before they become sceptic. Thus wounds and vulnerability lead to healing only when they have been uncovered.

The most important part of pastoral care and counselling is listening and empathy. They are the key to a healing relationship. According to the WCC Study Document (1997:85) listening skills, the ability to empathize with persons in a vulnerable and difficult situation and the willingness to share the pain and grief in a counselling encounter, are the main qualities, which should be looked for when selecting potential counsellors. Counselling is based on the skilled and careful use of relationship within which the expression of thoughts and feelings and the exploration of behavioural patterns, which may be causing concern, are facilitated. Aims of counselling are to enable HIV/AIDS orphans as heads of households to explore their thoughts, feelings and behaviour in order to reach clearer knowledge and understanding of themselves and as a result find strength and resources to cope more effective with life.

Empowerment is necessary to help individuals make decisions about their lives. This is especially important in counselling with AIDS orphans who have been disempowered on so many levels. As part of the counselling process it is also necessary to examine some core characteristics. According to Lartey (2003:88) these characteristics are expressed in nonverbal ways such as through gestures, tone of voice and facial expression.

Listening is the fundamental skill in counselling. It is about being able to listen to people, to understand what is it that they mean, and what their needs are. Gibson et al (1999:19) argue that having someone to pay attention to what you say and

94

take it into serious consideration makes people feel worthwhile. This is especially necessary for HIV/AIDS orphans. Finding out how people feel and reflecting on their experience may, according to Lartey (2003:72), help persons to begin again to weave a thread of continuity through their lives.

Empathy involves understanding correctly another person's state of mind and point of view. It is a learned skill that refers to the caregiver's ability to utilize the common bond of humanity and to therapeutically draw upon their own experience of thinking and emotion in a way that allows them to access and understand the experience of the other (Swinton 2001:141). Carers have to understand that some HIV/AIDS orphans may have no formal religious belief and no contact with a spiritual community. Even in such cases forgiveness and self-acceptance can be initiated. Thus Zurheid (1997:51) argues that empathy might be seen as the grace "which is sufficient" In other words God communicates God's power in the midst of tragic suffering. Empathy in this context may mean the ministry of presence. Companionship is what the HIV/AIDS orphans need, since they are often isolated from meaningful human contact. They need people who can talk sense to them. For those who do believe in God, an empathetic person may represent God's presence. Those who are not religious, on the other hand, will experience human presence, which represents the humanness or "ubuntu" of the African context. Helpers should be able to enter the world of the AIDS orphan deeply enough to understand their struggles with the problem situation in which they find themselves, and to identify opportunities for effective problem management and opportunity development.

6.4   Summary

It has been shown that HIV/AIDS orphans as heads of households who have no adult caregivers find themselves in an extremely difficult situation. The loss of the parental figure in their lives leaves them with wounds and without direction to approach life. This study concludes that it is necessary for HIV/AIDS orphaned children to find positive support networks. Ideally family, which includes nuclear

and extended families, are the primary support system. Secondary networks are the community, school (teachers and peers), religious leaders and the religious community. These positive support networks play a vital role in caring for and supporting HIV/AIDS orphans. However, the reality of these orphans is often that families reject them, stigmatise, discriminate against and isolated them. Family often fails these AIDS orphans. This leaves them with the traumatic experience of living in poverty, being without an income while have to care for siblings. Some of the orphans are homeless and face all sorts of abuse on a daily basis.

Pastoral care and counselling among persons affected by HIV/AIDS, plays an important role in the caring and healing process. Home Based Carers and Community Based Carers take the lead in identifying vulnerable homes and children infected and affected by the HIV/AIDS pandemic. There are also some churches, which feel called to truly being a healing community. However, what is being done is not nearly sufficient. Churches can initiate a new type of ministry, which involves both churches, and community based organisations. Working together towards helping HIV/AIDS orphans as heads of households and other vulnerable children, will probably be more effective than the present separate endeavours.

CHAPTER 7
RESEARCH FINDINGS

7.1   Introduction

This final chapter serves to assimilate the information gathered by means of literature and empirical research. This chapter will outline and evaluate the implications of the research findings obtained during the field or qualitative research conducted among HIV/AIDS orphans as heads of households and children who have been orphaned due to other circumstances, with reference to the literature study.

7.2   Problem Statement and Aims

HIV/AIDS orphans who function as heads of households find themselves in an ongoing traumatic situation. Sometimes their lives are in danger. First of all they have to nurse their ailing infected parents and witness their death, which already leaves them traumatised. After the death of their parents, the children are compelled to assume a position of control in the household – a position for which they are not equipped. More often than not they are isolated from their extended family and the community because of the stigma attached to HIV/AIDS. The growing numbers of HIV/AIDS orphans has impacted on extended families. Uncles and aunts who used to voluntarily take care of orphans are not doing so any longer. Some factors contribute to this decline of "ubuntu". One is *fear* which leads to stigmatisation and discrimination. This negatively affects the "ubuntu" that Africans used to have. Another is *poverty* since families lack adequate resources to feed, clothe and counsel HIV/AIDS orphans. Yet another factor is the *cost* of treating illnesses caused by HIV/AIDS. Funeral expenses also contribute to the financial toll exacted by HIV/AIDS.

In light of the problems surrounding HIV/AIDS orphans as heads of households the main research questions were designed to gather information on the

relationship between extended families and HIV/AIDS orphans who head households, on the experiences of the HIV/AIDS orphans, and on the vision of the future that these orphans have or do not have. The aims and objectives of the study were to listen to the experiences of some HIV/AIDS orphans who find themselves in the position of heads of households and to establish whether HIV/AIDS orphans may possibly be even worse off than children who have been orphaned on account of circumstances other than HIV/AIDS. In other words, does the fact of HIV/AIDS make a difference? The study was also interested in what the effects would be of the traumatic experiences occurring in specific developmental stages and how help could be geared toward the stage in which an orphan experiences the loss of parents and shoulders the burden of having to take care of siblings. The aim of the study was to provide informed suggestions on how these orphans could best be helped. Here the churches can play a role to support HIV/AIDS orphans who are forced to take responsibility of households in the absence of their parents or the extended family. The roles of Non-governmental Organizations (NGO's), schools, the community and government were also investigated. The study has shown that support on various levels is needed – financial, social, educational, emotional and spiritual – in order to facilitate the healing and full development of these children.

The literature has revealed that not too many studies have been conducted among HIV/AIDS orphans who function as heads of households. The contribution of this study is its holistic approach of focusing on the psychological, emotional, and spiritual welfare of the children.

7.3   Methodology and findings

The exploratory study identified Bophelong as an appropriate area of research among HIV/AIDS orphans as heads of households and children who had been orphaned by other causes than HIV/AIDS. The focus was on adolescents. Semi-structured interviews were selected as the main approach to this study. Data was collected by means of interviews and analysed. It was interpreted through the

98

lens of means of the developmental psychological model of Erikson, expanded on by others. The study has shown that the children affected by HIV/AIDS, are not only physically impoverished, but also psychologically, socially, and spiritually. They suffer from fears, depression, stress, anxiety, stigmatisation and discrimination, isolation, and are often scorned by peers. The essential relationship within the extended family is destroyed, which leaves the AIDS orphans even more vulnerable that they would have been as orphans due to causes other than HIV/AIDS.

The study has shown that HIV/AIDS orphans almost always come from poor families who are economically deprived. Stigmatisation and discrimination exacerbate the already traumatic impact of HIV/AIDS on infected and affected children. HIV/AIDS still remains a highly stigmatised disease. Interviews with the HIV/AIDS orphans revealed the following:

- Under-aged HIV/AIDS orphans are often deprived of their legal and human rights. They cannot, for instance, access grants because they have no relevant identification. Often members of their extended families abuse their rights. They may also become a soft target for criminals and abusers.
- HIV/AIDS orphans experience psychological trauma on account of witnessing their parents' illness and death (or departure), carrying the responsibility of caring for sick parents and, after their death, for siblings. Another traumatic experience is the absence of adult help, guidance, love and security. Traumatized orphans suffer damage to the basic structures of their lives. They lose trust in themselves, in other people, and in God.
- The socio-economic circumstances of HIV/AIDS orphans in child headed households often force them to drop out of school, in order to find ways of providing for the family.

The psychosocial development of the children was investigated in order to gain understanding of the effects of HIV/AIDS on orphans who, of necessity, find

themselves to be heads of households. Regression is often the result of the loss of parents, since parents provide physical and emotional security for children. It is traumatic for children to discover that their parents are physically unavailable. This is exacerbated when their subsequent caregivers are inexperienced, immature adolescents who are generally not up to the task of providing for younger children what they need.

Adolescents who are still searching for their identity, must cope with physical changes, often feel misunderstood and are not able to cope with the pressure put on them, and are prone to depression. When the additional pressure of having to take care of siblings exacerbates this, their situation becomes even more difficult and unhealthy.

Parental illness, especially when HIV/AIDS related, has an impact on children's psychological well-being and behaviour. Depression, anxiety, and low self-esteem are the resultant feelings, which often lead to acting out. They often exhibit sociopathic behaviour such as stealing, truancy, aggression and running away. Abandonment by the surviving parent also has a psychological impact on children who have already experienced the loss of one parent. They experience a prolonged period of bereavement, most often without the help, guidance, comfort and security that adults can provide. Here the church can play an important role by means of pastoral care. HIV/AIDS orphans, who are heads of households, can receive the help and guidance of the faith community when confronted with new challenges and searching for opportunities. Cognitive development is all about challenges and opportunities. Here the guidance of the church can be invaluable.

Positive social networks have a key function as well, since they provide a sense of social acceptance, identity and values. When the primary structures (family or extended family) fail, secondary structures should step in and assure that HIV/AIDS orphans are protected from all types of abuse (physical, emotional, psychological, social, sexual) and receive what they need on all levels. Along

100

with the church, schools can play a significant role in the socio-emotional development of the children. These institutions should not participate in the rejection and isolation of these children because of the stigmatisation of HIV/AIDS. If the church community remains true to its calling, such adolescents can be helped to develop a sense of identity and realise that God and God's people love and accept them unconditionally. Isolation from people and a lack of intimacy with God can cause these vulnerable young people to lose all hope.

Chapter five reports on the empirical research conducted among HIV/AIDS orphans as heads of households in the South Africa. Pertinent information includes the following:

- that child headed households are generally those where the main caregiver is younger than 18;

- that in South Africa there are 840 000 children who have lost their mothers because of HIV/AIDS and the number will be approximately 3 million by 2015;

- that extended families who used to voluntarily take care of orphans do not do so any longer and therefore orphans are often forced to live alone and fend for themselves;

- resources of HIV/AIDS orphans such as such as food, money and clothing are limited which often results in their dropping out of school to look for jobs;

- that the stigma associated with HIV/AIDS leaves HIV/AIDS orphans without social support;

- that these orphans are likely to be malnourished, are prey to illness and do not receive sufficient medical and health;

- that poverty is the root cause of their physical problems, but often neglect and discrimination by adults in whose care they have been left, are contributing factors;

- that orphans and other affected children face every kind of abuse and risk, including becoming infected with HIV/AIDS themselves as they are often forced into exploitative and dangerous work including exchanging sex for money, food, protection and shelter.

7.4   Main Research Findings

The research findings of the empirical study conducted among HIV/AIDS orphans as heads of households in Bophelong exposes some of the effects HIV/AIDS has on orphans who function as heads of households. The study reveals that a substantial number of children are being left orphaned on account of HIV/AIDS. The children are also traumatised by the events and their consequences. They are stressed out because of having witnessed the illness and death of their parent(s), and because of having to bear the brunt of negative comments and reactions from neighbours, peers, teachers and religious community. Marry, Zolile and Maria have succeeded to manage this stress and are doing well at school. However, Lucky's stress has pushed him out of school. Tebogo has not managed to return to school after having left on account of his mother's illness. After her death he had to assume the adult role of looking after the household and siblings.

Mary's sister Dolly has carelessly risks her life after her mother's death. She got involved in an unprotected sex, which resulted in her having a baby. This, however, was an eye opener to her. She was remorseful about the turn of events and continues to attend school. When she is at school the boyfriend's parents take care of the child. Even though she has had a child before her elder sister, she does not use that to humiliate and undermine her sister. It is their relationship of respect and love for each other that has helped them to survive. Marry shares her problems with Dolly and vice versa. Dolly is Marry's social partner and friend with whom Marry sharing her problems of being a child who has to take responsibility for heading a household. They believe that, if they should tell peers at school about you situation, they will gossip and laugh about it. However, if one shares it with family, they will help to solve the problems.

Tebogo lives with brothers who have been severely affected by HIV/AIDS. After the death of their mother they find it difficult to spend time at home as a family.

They do attend school, but their life has changed dramatically. Tebogo fears that the friends of his brother who is involved with drugs will someday come and injure their family. Both Marry and Tebogo are not afraid to take up the responsibility of caring for their siblings. Even though they live in impoverished circumstances, they have accepted the death of their parents because of HIV/AIDS. These untimely deaths took place at a time when, developmentally speaking, they were not ready to assume their new responsibilities without the assistance of the adults. They need to live with adults who will care for them, love them and treat them as if theirs. However, their caregivers treat them as second-class citizens, as people without rights. Instead of providing the love they need, these adults cheat them out of their property. They also report the children to social workers complaining that they behave badly, in the hope that they will be sent to orphanages. This nearly happened to Lucky. His paternal aunt plotted that he be sent to Durban to herd cattle so that she could have the house.

Marry and Tebogo are members of a church who attend regularly. Tebogo does not attend so often any more, because his first priority or to provide for food and electricity in their home. Marry's faith community is supportive and visits them regularly. Marry and her family are provided with pastoral care and counselling. Not all churches, however, seem not to understand the role they could play in the context of HIV/AIDS orphans as heads of households. The family has the first responsibility for child rearing and caring for children (Matsumoto 1994:73), but when the family and community fail, the church as a "healing community" (WCC Document 1997:77) can play a supportive role that can make a difference to HIV/AIDS orphans who function as heads of households.

The traumatic experiences of HIV/AIDS orphans as heads of households and children, who have been orphaned due to other circumstances, are similar. The field research done for this study shows that children orphaned by causes other than HIV/AIDS, such as murder or car accidents, are robbed their property by family, relatives and neighbours, who took their documents as if they want to

arrange something that will benefit these children but at the end these children end up loosing everything. In Zolile's case, for instance, the aunt took all his documents: birth, baptismal and mother's death certificate, as well as the title deed that was registered in his name. At this point in time he is not sure whether the house is still in his name or whether the aunt has put it on her name.

The study has also shown that orphaned children are often given extra work and chores by foster parents, especially where social workers do not visit regularly. Often after six months or so the orphaned child leaves that home to rather live on the streets. HIV/AIDS orphans as heads as households live in fear of being the victims of abuse. In the case of Tebogo there is the fear that the siblings are out of control. Lack of experience for their task as heads of households and caring for and rearing children, often results in stress, which can even lead to suicide. HIV/AIDS orphans who are responsible for households often panic when younger siblings cry because they are hungry. The responsible child does not know what to do and often simply bursts into tears. HIV/AIDS orphans are compelled to leave school to look for jobs in order to fend for the siblings.

HIV/AIDS has done damage to the lives of people, young and old. Many children have been orphaned. Some children still have parents who are living with HIV/AIDS. The burden of caring for these parents is also a formidable one. In light of the overburdened families who do not seem able to cope with the consequences of HIV/AIDS, the dwindling sense of "ubuntu" and the ever-present poverty, a united front against HIV/AIDS is needed in order to address the problems. Churches, government and communities have the task of destigmatising HIV/AIDS. Here churches especially can play a leading role. All human beings need to engage in the fight against HIV/AIDS and promote love, acceptance and respect people's rights. Learning to understand the experiences of people living with HIV/AIDS will help people to know how to respond to their situation. This also goes for pastoral caregivers who will do a better job if they understand the situation, the experiences and the feelings of those infected and

affected by HIV/AIDS. The contribution of this study is to help foster such understanding, especially within the faith community.

Financial assistance for the education for orphaned children will help to mitigate the impact of HIV/AIDS on them. Many orphaned students are leaving school because of the high costs of school fees, uniforms and books and the lack of food at home. Some girls leave school and risking their lives when trying to earn a living for themselves and their siblings by means of commercial sex, which exposes them to HIV/AIDS. If orphaned students could be exempt from school fees and be supplied with books and uniforms by churches and NGO's, that could help to reduce the number of orphans leaving school in order to try and find jobs. Home and Community Based Care in Bophelong is operating and active. In cases where children are left to take care of sick parents these organisations play a major role in helping to support the children in their task. They also teach the children how to handle the situation. Since some of the members of the organisation are trained counsellors, they play a major role in reducing the stress levels of HIV/AIDS orphans as heads of households.

Social Development and Welfare is providing child support grants, care dependence grants and disability grants to the needy children. HIV/AIDS orphans as heads of households who are less than 21 years old and heads of households however are not acknowledged as being the guardians of their siblings. This is traumatic, because even though some of them have legal identity documents and are allowed to vote, their access to, much needed benefits is restricted. Some secondary schools have bursaries available for poor students, including orphans. Especially the well-developed schools have such benefits for students.

Peers at school can act as social support to orphaned children. Marry, however, chooses her sisters to be her social support rather than peers at school, since the children often mock those with problems rather than support them. Lucky is part of a group of orphans like himself. They form a support system for one another.

He says that it is better to be with people whose problems are similar to yours. They are able to console one another. Educating school pupils about HIV/AIDS and its effects can help many people. Such education can benefit all because reticence to help these children is often caused by ignorance. People do not know whether one can contract HIV by just living with someone with HIV/AIDS. Having information on HIV/AIDS in primary and secondary schools can help to lessen the impact of HIV/AIDS on orphans and people living with HIV/AIDS.

7.5   Comments on the Research

The research in this study was done in five households. The stories of five children were told. Given the epistemological approach of the study, it does not pretend to be able to generalise the results of such a small sample. The aim was to tell these stories, bring them into dialogue with the literature and gain a better understanding of the dilemma in which children who have been affected by HIV/AIDS find themselves, especially those who are forced to take up responsibilities well beyond their years. Due to the stigma associated with the HIV/AIDS pandemic it was not easy to identify the research participants. I am happy to have found these willing respondents and thank them for their participation.

7.6   Recommendations for Further Research.

These results of this study beg future research in the following areas:

- The role of churches in identifying and supporting orphans in child headed households.
- Stress experienced by HIV/AIDS orphans in child headed households due to HIV/AIDS.
- The role of educators in encouraging orphans in child headed households to build a future for themselves.

7.7   Summary

This study has addressed the traumatic experiences of HIV/AIDS orphans who function as heads of households. The research has shown that steps need to be taken to help and support HIV/AIDS orphans as well as children who have been orphaned due to circumstances other than HIV/AIDS. Since there are limited studies available on child headed households in South Africa, much more needs to be done. The findings of this study confirm that HIV/AIDS orphans as heads of households experience social, psychological, emotional, and spiritual pains and trauma. Each of these fields also begs further investigation. For example, some of these pains are caused by ineffective of family support. This study has shown that most of the extended families are not supportive of the HIV/AIDS orphans in child headed households.

Positive network support can go a long way to change the emotional, psychological, social and spiritual breakdown of the lives of HIV/AIDS orphans who find themselves with the responsibilities of heads of households and children orphaned by other circumstances. This study proposes a joint approach of government, churches, communities and NGO's to address the appalling situation of the growing number of orphans and child headed households in South Africa.

University of Pretoria (Practical Theology) – Maqoko, Z (2005)

Participant's name……………………   Date……………….

Researcher……………………………

INFORMED CONSENT

1.   Title of study   :   HIV/AIDS orphans as heads of households:
                                         A challenge to Pastoral Care.

2.   Purpose of the study: The goal of this study is to examine experiences of
                                         HIV/AIDS orphans as heads of households.

3.   Risks and discomforts: There are no known risks or discomforts
                                         associated with this project.

4.   Benefits   :   As I understand there are no known direct benefits.
                                         However, the results of the study may help the
                                         researchers for a better understanding of what the
                                         psychological, emotional and spiritual impacts of
                                         HIV/AIDS on orphans as heads of households are.

5.   Participant's rights   :   The children in my care can withdraw from the
                                         study at any time without any hassles.

6.   Confidentiality   :   I understand that the results will be kept
                                         confidential unless I ask that they be released. The
                                         results of this study may be published on
                                         professional journals or presented at professional
                                         conferences, but the child's identity will not be
                                         revealed unless required by law.

I understand child's rights in my care as a research participant, and I voluntary consent to his/her participation in the study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

_____   _____

Legal guardian's signature   **Date**

ANNEXURE 2

This is a sample of questions used in this semi-structured interview with the participants in this study:

What is you name and how many are you in the house?

How old are?

What grade are you doing?

Would you please tell me about you family?

How is your relationship with your extended family?

What are your experiences as the head of the household?

Would please tell me about your experience at school?

How is your relationship with your neighbours?

Are your associated with any religious organization?

What are you future expectations? How do you see your future?

BIBLIOGRAPHY

Adams, G R & Berzonsky, M D 2003. *Blackwell handbook of adolescence.* Oxford: Blackwell*.*

Ayieko, M A 1997. *From single parents to child-headed households: The case of children orphaned by AIDS in Kisumu and Siaya districts.* New York: University of Illinois.

Bless, C & Higson-Smith, C 1995. *Fundamentals of social research***:** *An African perspective***.** 2nd ed. Cape Town: Juta.

Books, S 1998. *Invisible children in the society and its schools.* Mahwah, NJ: Lawrence Erlbaum Associates.

Bray, R 2003. Predicting the social consequences of orphan-hood in South Africa**.** *African Journal of AIDS Research,* 2(1), 39 – 55.

Brookes, H; Shisana, O & Richter, L 2004. *The National household HIV prevalence and risk survey of South Africa.* Cape Town: HSRC*.*

Cairns, K 1999. *Surviving Paedophilia: Traumatic stress organized and child sexual abuse.* Stoke on Trent: Trentham Books*.*

Campbell, A V 1986. *Rediscover pastoral care.* 2nd ed**.** London: Darton, Longmann and Todd Ltd.

Center for Policy Studies 2001. *AIDS orphans in Africa: Building an urban response.* Cape Town: Creda Communications.

Chabillal, A J 2004. A Socio-educational study of the impact of HIV/AIDS on the adolescent in child headed households. Unpublished Masters Dissertation, University of Pretoria.

Clinebell, H 1979. *Growth and Counseling: Hope-centered methods of actualizing wholeness.* Nashville: Abingdon.

Cook, A S & Dworkin, D S 1992**.** *Helping the bereaved: Therapeutic interventions of children, adolescents and adults***.** New York. Basic Books.

Denzin, N k & Lincoln, Y 2000. *Handbook of qualitative research* 2ND ed. Thousand Oaks: Sage.

Diagnostic and Statistical Manual of Mental Disorder – *DSM IV* 1994*.* Washington, DC: American Psychiatric Association.

110

Douglas, J D; Hillyer, N; Bruce, F F; Guthrie, D; Millard, A R; Packer, J I & Wiseman, D J 1992. *New Bible dictionary* 2nd ed. Leicester: Inter-varsity press.

Erikson, E H 1963. *Childhood and Society.* London*:* Paladin Grafton Books*.*

Foster, G 2002. Beyond food and education: Psychosocial well being of orphans in Africa. *ACTA PAEDIATRICA 91*. 502 – 504.

Frankfort-Nachmias, C & Nachmias, D 1992. *Research Methods in the Social Sciences.* 4th ed. London: Edward Arnold.

Granot, T 2005. *Without You: Children and young people growing up with loss and its effects.* London, Philadelphia: Jessica Kingsley Publishers*.*

Geldard, K & Geldard, D 2002. *Counseling children: A practical introduction.* 2nd ed**.** Thousand Oaks: Sage.

Gelles, R J 1995. *Contemporary families*: *a Sociological view.* Thousand Oaks: Sage.

Gerkin, C V 1997. *An introduction to Pastoral Care***.** Nashville: Abingdon.

Gibson, K, Swart, L, Sandenberg, R 2002. *Coping and Counseling.* Cape Town: Oxford.

Gillis, H 1994. *Counseling young people.* Pretoria: Kagiso.

Grossoehme, D H 1999. *The pastoral care of children.* London: The Haworth pastoral.

Gow, J & Desmond, C. 2002. *Impacts and Interventions*: *The HIV/AIDS epidemic and the children of South Africa.* Pietermaritzburg: University of Natal.

Guest, E 2003. *Children of AIDS: Africa's orphan crisis* 2nd ed. London: Pluto.

Hepburn, A 2002. Increasing primary education access for children in AIDS-affected areas. *Perspective in Education* 20(2), 87 - 98.

Herman, J 1997. *Trauma and Recovery.* New York: Basic Books*.*

Hiltner, S 1958. Preface to Pastoral Theology. Nashville: Abingdon.

Houle, M M 2003. *AIDS in the 21st century: what you should know.*

Bekerley Heights, N.J: Enslow.

Kail, R V & Cavanaugh, J C 1996. *Human development*. Mexico City.
Brooks/Cole.

Kübler-Ross, E 1991. *On Life After Death*. California: Celestial Arts.

Kvale, S 1996. *Interviews: an introduction to qualitative researching***.** Thousand
Oaks: Sage.

Lartey, E.Y 2003. *In living color: An intercultural approach to pastoral care and
Counseling* 2nd ed. United Kingdom: Jessica Kingsley.

Levin, L C 2001. *The Holocaust and Meaning: Three generations of experience:*
Unpublished Master's Dissertation: University of Pretoria.

Lindblade, K A; Odhiambo, F; Rosen, D H & DeCock, K M 2003. Health and
nutritional status of orphans < 6 years old cared for by relatives in
Western Kenya. *Tropical Medicine and International Health* 8 (1), 67-72.

Loughry, M & Eyber, C 2003*. Psychosocial concepts in humanitarian work
with children: A review of the concepts and related Literature.*
Washington, DC: The National Academic Press.

Manegold, J; Richter, L & Pather, R 2004. *Family and community interventions
for children affected by AIDS.* Cape Town: HSRC

Martin, A C & Colbert, K K 1997. *Parenting: A Life Span.* New York:
McGraw-Hill.

McIlveen, R & Gross, R 1997. *Developmental Psychology*. London: Hodder
& Stoughton.

Meier, D P; Minirth, F B; Winchern, F B & Ratcliff, D E 1992. *Introduction to
Psychology and Counseling: Christian perspective and applications.*
Grand Rapids, Michigan: Baker Books.

Moutona, J 2001. *How to succeed in your master's and doctoral studies: A South
African guide and resource book*. Pretoria: Van Schaik.

Nardoni, E 2004. *Rise up, O Judge: A study of justice in the Biblical world.
Peabody, Massachusetts*: Hendrickson*.*

Neuman, W L 1997. *Social Research Methods*: Qualitative and Quantitative
Approaches 3rd ed. Boston: Allyn and Bacon.

Newman, B M & Newman, R P 1999. *Development through life: A psychosocial approach 7Th ed.* London: International Thomson.

Ng'weshume, J, Boerma, T, Bennett, J & Schapink, D (eds) 1997. *HIV prevention and AIDS care in Africa: a district level approach.* Amsterdam: Royal Tropical Institute.

Payne, S; Horn, S & Relf, M 1999*. Loss and bereavement.* Philadelphia: Open University Press.

Pennells, M & Smith, S C 1995. *The forgotten mourners: guidelines for working with bereaved children.* London: Kingsley.

Pennington, D C 1986. *Essential Social Psychology.* New York: Edward Arnold.

Pharoah, R 2004. A Generation at Risk. *HIV/AIDS, vulnerable children and security in Southern Africa.* Pretoria: Institute for Security Studies.

Psychology Today 2005. *Bereavement*. Sussex publishers. http://health.yahoo.com/centers/relationships/96408490.html

Reinharz, S 1992. *Feminist methods in social research.* New York: Oxford University*.*

Richter, L, Manegold, J & Panther, R 2004. *Family and community interventions for children affected by AIDS.* Cape Town: Human Sciences Research Council.

Rosa, S & Lehnert, W 2003. *Children without adult caregivers and access to social assistance.* Hosted by the Children's Institute, University of Cape Town and the Alliance for Children's Entitlement to Social Security 20 – 21 August 2003.

Rosa, S 2004. *Counting on children: Realizing the right to social assistance for child-headed households in South Africa***.** Children's institute Working paper number 3. University of Cape Town. August 2004**.**

Rubin, H J & Rubin, I S 1995. *Qualitative Interviewing: The art of Hearing.* London: Sage.

Skweyiya, Z S T 2002. *Child protection week: Conference on children affected by HIV/AIDS.* Eskom Conference center – Midrand 2 June 2002.

Sloth-Nielsen, J 2004. *Realising the rights of children growing up in child-headed households: a guide to laws, policies and social advocacy.* Cape Town: Creda Communications.

Smelser, N J 1981. *Sociology.* Englewood Cliffs, New Jersey: Prentice Hall, Inc.

Stairs, J 2000. *Listening for the soul: Pastoral care and spiritual direction.* Minneapolis: Fortress.

Swinton, J 2001. *Spirituality and mental health care. Rediscovering a 'forgotten' dimension.* London: Kingsley.

Tedeschi, R G & Colhoun, L G 1995. *Trauma and transformation: Growing in the aftermath of suffering.* Thousand Oaks: Sage.

Togni, L 1996. *Sociology of Africa.* Pretoria: Kagiso.

UNAIDS/UNICEF/USAID 2004. *Children on the Brink: A joint report of New Orphans estimates and a framework for action.* USAID*.*

UNICEF 2003. *Africa's Orphaned Generations.* New York: UNICEF.

UNICEF 2003a. *Orphans and other children affected by HIV/AIDS.* New York: UNICEF.

UNICEF 2003b. *Fighting HIV/AIDS: Strategies for success 2002 – 2005.* New York: UNICEF

Van Aarde, A 2001. *Fatherless in Galilee: Jesus as Child of God.* Harrisburg, PA: Trinity Press.

Van Dyk, A 2001. *HIV/AIDS Care and Counseling: A multidisciplinary approach 2nd ed.* Caper Town: Pearson Education South Africa.

WCC Study Document 1997. *Facing AIDS: The challenge, the churches' response.* Geneva: World Council of Churches

Weinreich, S & Benn, C 2004. *AIDS: Meeting the challenge data, facts, background.* Geneva: WCC Publication.

World Bank Policy Research Report 1999. *Confronting AIDS.* New York: Oxford.

The World Bank 2002. *Education and HIV/AIDS: A window of hope.* Washington, DC: The World Bank

Zurheide J R 1997. *When faith is tested: Pastoral responses to suffering and tragic death.* Minneapolis: Fortress.