THE EXPERIENCE OF AIDS ORPHANS LIVING IN A TOWNSHIP

by

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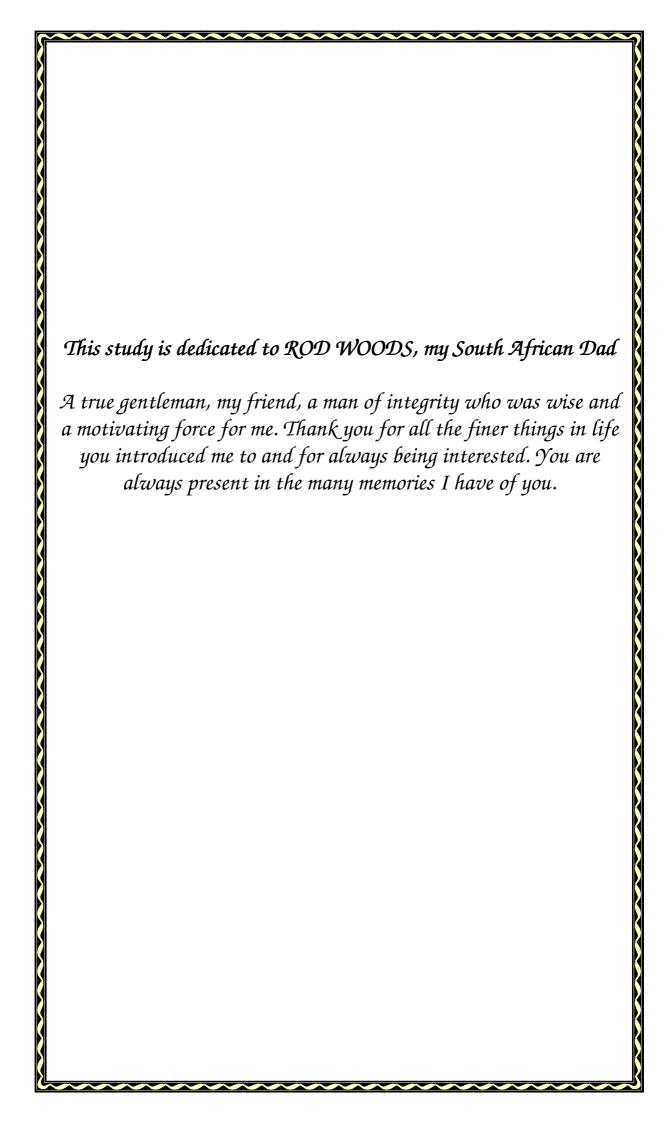
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"... Pure and undefiled religion before God the Father is this: to visit widows and orphans in their time of trouble and to keep oneself from being polluted by the things of this world."

James Ch1 v 27



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ABSTRACT

One of the challenges facing health care professionals today is the phenomenon of rendering care to children who have been orphaned in the AIDS pandemic. The number of AIDS orphans in South Africa has risen out of all proportion and is causing existing health and social structures to become stretched in providing care to this vulnerable population of children. The objectives of this study are to explore and to describe the lived experience of children living in a township who have become AIDS orphans and to develop broad guidelines for Primary Health Care Nurses (PHCN's), related professionals and partners involved in the care of AIDS orphans living in a township. The theoretical grounding of this study is found in Kotze's Theory on Nursing Accompaniment (Kotzé, 1998:3).

The proposed research design was based upon a qualitative study using an explorative, descriptive, contextual and phenomenological strategy of inquiry. Data was collected by means of in-depth interviews from a purposively selected sample and then analysed using the steps of qualitative data analysis proposed by Tesch (in Creswell, 1994). Guba's model was used to assess the trustworthiness of the qualitative data. Based upon the findings, guidelines were developed to assist PHCN's related professionals and partners involved in the care of AIDS orphans living in a township. Through this study the goal of the researcher was to give a voice to AIDS orphans living in a township and to represent accurately their lived experience.

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CHAPTER ONE

OVERVIEW OF THE RESEARCH STUDY

"In the dry timber of African societies, AIDS was a spark. The conflagration it set off continues to kill millions, here is why" (Guest, 2001:4).

1.1 INTRODUCTION

Imagine your life this way. You get up in the morning and have breakfast with your three children. One is already doomed to die in infancy. Your husband works 200 miles away, comes home twice a year, and sleeps around in between. You risk your life in every act of sexual intercourse. You go to work past a house where a teenager lives alone, tending young siblings without any source of income. At another house, the wife was branded a whore when she asked her husband to use a condom, beaten silly and thrown out onto the street. Over there lies a man desperately sick without access to a doctor, clinic, medicine, food, blankets or even a kind word.

At work you eat with colleagues and every third one is already fatally ill. You whisper about a friend who admitted she had the plague and whose neighbours stoned her to death. Your leisure is occupied by the funerals you attend every Saturday. You go to bed fearing adults your age will not live into their forties. You and your neighbours and your political and popular leaders act as if nothing is happening. Across the southern quadrant of Africa, this nightmare is real. (Guest, 2001:4-5). Vulnerable children are no longer children as the responsibility of raising the next generation falls on their shoulders. They are shocked, bewildered, grief-stricken and suffering severe economic hardship.

This study will explore the lived experiences of AIDS orphans living in a township.

1.2 BACKGROUND

"I decided I would rather go to bed hungry than to continue to beg for food. My mother died of HIV/AIDS, I cried of a broken heart to think that I was now an AIDS orphan;" (Mamakete, 14 years old <u>in</u> Mathe, 2003:13).

"AIDS (Acquired Immune Deficiency Syndrome) has devastated the social and economic fabric of African societies and made orphans of a whole generation of children" (Matshalaga, 2002b:1). Like the virus itself, the AIDS crisis mutates rapidly. AIDS orphans in South Africa, as in other African countries, suffer from recurrent psychological trauma. It starts with the illness and death of their parents and it is followed by cycles of poverty, malnutrition, stigma, exploitation, sickness and often sexual abuse. The figures concerning those affected, which are staggering, offer various predictions regarding the number of orphans left in the wake of the pandemic. As many as 19 million are dead already and there are 13 million grieving children around the world. With 34 million people currently infected and likely to die during the next decade, many more children face being orphaned (Guest, 2001:4). The United States Agency for International Development (USAID, 2002:2) estimates that 44 million children under 15 years in 34 developing countries will have lost one or both parents by 2010, mostly to AIDS. The reliability of these statistics needs to be questioned for the following two reasons:

AIDS in South Africa is not a notifiable disease, therefore the true numbers of those dying of AIDS and the true numbers of AIDS orphans left as a result are not known exactly. The statistics for AIDS orphans are calculated using assumptions, such as the average number of children per mother, a reduction in fertility and increase in infant deaths caused by AIDS.

Africa is home to 95% of the world's 13 million orphans as a result of HIV/AIDS. As the AIDS pandemic spreads and mortality increases, so do the number of orphans. Before AIDS approximately 2% of all children in developing countries were orphaned (Foster, 2002:1). After AIDS became pandemic, the percentage of orphan children rose to between 9 and 11% (Bradshaw, 2002:58). To give this some context, around the world such calamities as war, famine and disease make orphans of about 2% of the population. In countries hardest hit by HIV/AIDS, 8% to 34% of children have been orphaned through the HIV/AIDS pandemic. The startling reality of these figures hits home when one realises that 9 out of 10 children who have been orphaned due to AIDS live in sub-Saharan Africa and that by 2010, sub-Saharan Africa will be home to 10 million orphans (Robinson, 1999:9).

"The AIDS pandemic in Africa is reducing life expectancy, increasing mortality, reducing fertility, leaving more men alive than women and producing millions of AIDS orphans. Unless a medical miracle occurs, almost all the 24 million of Africans infected with the virus at the beginning of 2000 will die. Each day 6000 Africans die from HIV/AIDS and a further 11,000 are infected with HIV" (Henderson, 2002:4).

At the end of 1999 an estimated total of 11.2 million children had been orphaned by the HIV/AIDS pandemic and more than 90% of the children orphaned by AIDS live in sub-Saharan Africa. By the end of 2000 an estimated total of 13 million children had lost their mother or both parents to HIV/AIDS. Of the 13 million children orphaned by AIDS at the end of 2000, the greater majority (10.4 million) were under the age of 15 years.

So the devastation continues. Data from the United States Agency for International Development suggests that 19 Sub-Saharan countries will have a combined total of 40 million orphans by the year 2010, due to HIV/AIDS. The statistics demonstrate that one in every 3 children orphaned by HIV/AIDS is under 5 years of age. Studies by UNICEF also demonstrate that when a family member dies of HIV/AIDS, the income of the family falls by between 50 and 65%, whilst expenditure on health care quadruples. The orphans are the first to be denied their education when their extended families cannot afford to educate them (UNICEF, 2004:6). The latest available statistics demonstrate that 26.5% of South Africa's population (of 44.8 million) is infected with HIV (Bester, 2006:41). In the Eastern Cape, where this study will be carried out, 35% of the population is infected with HIV and 22% of all AIDS orphans in South Africa are resident in the Eastern Cape (Jacobs, et al, 2005:53).

Currently there are more people infected with HIV/AIDS living in South Africa than in any other African country (Bradshaw, 2002:4). This means that ultimately South Africa will have the highest number of orphaned children on the African continent. There will be significant costs incurred in caring for these children long- term. If no mechanisms are put in place, such costs will include an increase in the numbers of children living on the street, increased levels of juvenile delinquency, reduced literacy and a huge economic burden will be placed upon the state.

Orphaned children are not only traumatised by the loss of their parents (whose physical deterioration they have normally witnessed), but they also lack the necessary parental guidance through the critical stages of identity formation into adulthood. The children's ability eventually to participate constructively in social and economic life, could therefore be significantly reduced and will impact on the levels of juvenile crime.

A recent study by Bradshaw (2002:3) estimated the number of orphans in South Africa, using the statistics from the ASSA (Actuarial Society of South Africa), to be 2 million orphans in South Africa by 2015. This figure would be seen to be conservative based on the fact that most children are not independent of their parents by the age of 15 years. There is no universal definition for an orphan because there are different types of orphans. There are maternal orphans (children whose mothers have died), paternal orphans (children whose fathers have died) and double orphans (children who have lost their parents). This is further complicated by the fact that there is also no universal definition for a child. For some it is a person under the age of 16 years; for another it is a person under the age of 18 years. These discrepancies will be highlighted in the following discussion.

The most commonly used definition for an orphan is a child under the age of 15 years whose mother has died (Bradshaw, 2002:7). But orphans do not cease to have need of parenting on reaching 15 years of age. In addition, the loss of the father also has significant impact. The constitution of South Africa defines children as being persons under the age of 18 years, and most policy makers would agree that children under the

age of 18 years should not be expected to be self-supporting (Scofield, 2001:14). Whatever definition is used, the numbers of orphans are likely to peak in the year 2015 at approximately 2 million in the case of maternal orphans under the age of 15 years and 3 million maternal orphans who are under the age of 18 years. The number of paternal orphans under 18 years is expected to peak at 4.7 million in 2015 (Bradshaw, 2002:7). Over 60% of all orphans living in South Africa will be living with their grandparents, 20% will be living with other relatives, 10% will be living with their siblings and 10% will be living with non- related family, adopted, fostered or living with respective sons- and daughters-in-law (UNICEF, 2004:27).

It is imperative to understand the impact of AIDS deaths on households. It is unlike any other disaster such as drought or famine, because of the incremental nature of the pandemic. AIDS wears down extended family resources over a period of time, at the same time as the numbers of orphans are increasing. By 2010, 16 % of all children living in South Africa will be orphans. More that 10 percent of those orphans will be AIDS orphans (UNICEF, 2004:11).

The statistical data representing the AIDS pandemic, despite its irregularities, does offer useful implications, scales and trends of the pandemic. The statistics indicate that there is a serious problem that needs to be addressed and that the numbers of AIDS orphans is increasing as a result of the AIDS pandemic. It has been said that the AIDS pandemic could be as catastrophic for Africa as the Black Death was for Mediaeval Europe. The Bubonic plague wiped out roughly one third of Europe's population within 15 years in the 14th Century (Guest, 2001:7).

"The extended family is not a social sponge with infinite resources able to soak up the ever-increasing number of orphans affected by the AIDS pandemic" (Robinson, 1999:3). Blanket statements about the role of the extended family in Africa as a safety net, and assumptions that relatives will be ready and able to assist orphans in need, should be treated with caution. This is in the light of remembering that most of the AIDS orphans will have lost aunts, uncles, cousins and siblings in the HIV/AIDS pandemic. Children, who are unfortunate enough to slip through the safety net of extended family support, are especially vulnerable to disease, malnutrition, illiteracy, exploitation and also the risk of infection with HIV themselves. As the traditional family structures decay in the pandemic, the suffering of grandmothers and grandchildren increases as parents watch their children die and children watch their parents die. "It was a long parade to the grave yard, once a year for 5 years" an aged grandmother reports after she has buried another of her children. She thought that by raising eight children she'd insured herself against hardship in old age. She was wrong. By the year 2000 she had inherited the task of rearing eight of her children's children, without any increased financial support (Guest, 2001:17).

As the numbers of orphaned children in a community increase and uncles and aunts also die prematurely of AIDS, the traditional and first choice of caregivers becomes unavailable and ailing grandparents are therefore recruited to childcare. Grandparents are often the last resort as caregiver and agree to take the

AIDS orphans into their homes as all other relatives refuse. In some cases, however, what happens is that the burden of care for the frail grandparents falls to the younger orphans and so their childhood is lost in a heap of grief and mounting responsibility (Kilburn, 2002:2).

In the demise of grandparents and the realities of a migrant labour force the inevitable has occurred in that there are now increased numbers of children living on the street and increased numbers of orphan children living in Child-Headed Households (CHH's). In communities where the prevalence of HIV/AIDS has severely affected the community, the number of CHH's had risen. In neighbouring African countries, for example, Uganda, the prevalence of CHH's was 30/1000 in 1997. Considering that South Africa has the highest HIV infection rate on the continent of Africa, these statistics can be assumed to be far worse than were previously thought (Masland, 2000:28).

The researcher is a Primary Health Care Nurse (PHCN), with experience of working in a Primary Health Care capacity with AIDS orphans in Uganda, Zambia, Lesotho and South Africa. Whilst working as a volunteer at the House of Resurrection Haven in South Africa and subsequently as a PHCN in the clinics in the Nelson Mandela Metropole, the researcher gained experience in the care of AIDS orphans. It was during this time that the researcher became aware of the extent of the AIDS pandemic and how death, abandonment, rejection, socio-economic hardship and poor health plagued the lives of children who had been left as AIDS orphans.

1.3 PROBLEM STATEMENT

As a Primary Health Care Nurse working in the clinics in the Nelson Mandela Metropole, the researcher became overwhelmed by the needs of the AIDS orphans attending the clinics to access care and felt ill equipped to care for them. When speaking to other PHCN colleagues and related professionals, also working in Nelson Mandela Metropole, the researcher became acutely aware that many of her colleagues were equally overwhelmed by the needs of the AIDS orphans and also felt ill equipped to care for them.

The following cases of Molatela, Heather and Peter, who are AIDS orphans, and Ann, a community worker, describe the overwhelming needs of AIDS orphans.

Case One (Molatela)

"Our relatives don't come. They don't want to see us. I don't know why. Some of them came before my parents died. Right now, they don't come. No one visits us. I don't know why. They live close but we don't see them. When we last saw them it was at the funeral" (Guest, 2001:131). These are the words of Molatela, a 17-year-old girl from Sebokeng, a township outside Johannesburg South Africa. She and her siblings have been orphaned because of the death of their parents to HIV/AIDS. They live in a small shack and she is the main carer for her three siblings following the death of her parents. The eldest of her brothers is Malone, aged 14 years, Nakampe, 9 years, and then Pheega, who is 3 years of age and HIV-positive. There was no offer of help from the extended family.

Molatela has become the new mother to the family who were already traumatised due to caring for their sick parents until they died. "My father died first and we buried him on the Saturday ..." She trails off and looks panicky.

'I have forgotten the date... the funeral was very big and after we had buried him my mother died on the Sunday" (Guest, 2001:132). For four years Molatela and her brothers cared for their mother at home. "I looked after my parents until they died. My big brother helped with my father. He washed him and I washed my mother. No one else helped us ... they didn't come. I don't know why. Some of the neighbours brought food when they saw that my parents were sick, some didn't come at all because they knew that my parents had AIDS" (Guest, 2001:134). "Sometimes we didn't even have mealiemeal. Then we would have to borrow from our neighbours that day. Some would give me sugar and some would just say, 'No'. If they say that I can't have sugar then there is nothing that I can do. Sometimes we were just hungry and we would go to bed without anything to eat at all. At that time, I didn't know what to do. I talked to my brother. I said, "What can we do? We don't have food to eat" (Guest, 2001:135).

"She is doing the best she can to wash, cook and clean for a family of 5 and to organise the children and herself with regard to schooling, and keep a 3-year-old HIV-positive child well, as well as dealing with her own grief and loss concerning her parents" (Guest, 2001:137).

Case Two (Heather aged 9)

A visit to a semi-rural home found a 9-year-old called Heather taking care of her mother who was very seriously ill with infections that her immune system was unable to fight. There was also a disabled toddler and an HIV-positive baby. The 9-year-old was feeding, cleaning and nursing all 3 of the family members without any support. When asked what she wanted to do, she replied, "I want to be able to play" (Loening-Voysey, 2002:105).

Case Three (Peter age unknown)

"Sometime back I lost my mother. Before her death, we were struggling, scavenging discarded food from the rubbish dumps. My mother was the sole breadwinner but she was earning very little. Sometimes she would send us to beg for food. When she died we had no one to take care of us. We had no food or soap and were unable to go to school" (Green, 2002:2).

AIDS orphans such as Peter often find themselves wanting, because their basic needs are left unmet. They prostitute themselves to gain money to buy food and are vulnerable to abuse, exploitation and the risk of HIV/AIDS. They are prey to "Sugar Daddies" who will reward them for sex. The orphans need proper attention and protection (Guest, 2001:158).

Case Four (Ann a Community Worker)

"They were so quiet. She told me they were AIDS orphans, the children were all starving and ill; one was close to death. Horrified, I fetched all the food we had in the vehicle and went into one of the houses. There were three skeletal children; one had already died and the others were close to death. I couldn't believe it. There was no help for them all." This was the experience of a community worker on meeting a household of AIDS orphans during routine visits in her community near Johannesburg (Kazuo, 2000:42).

The research questions that arise from this problem statement are:

How do children living as AIDS orphans in a township experience life?

What can PHCN's, related professionals and partners do to care for AIDS orphans living in a township?

1.4 RESEARCH OBJECTIVES

This research study has a primary and a secondary objective:

The primary objective of this research study is to explore and describe the lived experience of AIDS orphans living in a township.

The secondary objective is to develop broad guidelines for PHCN's, related professionals and partners involved in the care of AIDS orphans living in a township.

1.5 CONCEPT CLARIFICATION

The terminology applicable to this research is as follows:

Experience

Experience can be defined as the "knowledge based on personal observation or contact: the events that one undergoes or suffers: referring to the sum total of the individual thoughts, feelings and events that have happened to the individual, either actual or perceived. It includes the internal environment (body, mind and spirit) as well as the external environment (physical, social and spiritual dimensions)" (Oxford English Dictionary, 2002:202). This study aims to explore and describe children's experiences of life as AIDS orphans living in a township.

Township

This is an urban black residential area in cities across the country of South Africa, where people previously disadvantaged under the Apartheid regime reside.

Informal Settlement

This is a previously unoccupied geographical area within the township, where people live in roughly assembled buildings and shelters. The Nelson Mandela Metropole in the Eastern Cape and has 179 Informal settlements holding 136 567 households - the 2nd highest number of informal settlements in South Africa (Anon, 2003b:3). According to the Labour Force Survey 2001, 38% of Eastern Cape residents live in informal settlements (Anon, 2003a:6).

Orphan

An orphan can be defined as a child who has been bereaved of his/her parents (Oxford English Dictionary, 2003:396). Orphans can, however, be classified as maternal orphans (children who have been bereaved of their mothers), paternal orphans (children who have been bereaved of their fathers) and double orphans (children who have been bereaved of both their mother and their father). Another definition of an orphan is a child under the age of 15 years whose mother has died (Bradshaw, 2002:7). For the purpose of this study an orphan will be considered as any child who has been bereaved of mother, father or both parents and who is below the age of 18 years.

AIDS Orphan

According to UNAIDS, an AIDS orphan is defined as a HIV-positive or negative child who, prior to the age of 15 years, has lost either mother or both parents to AIDS (Smart, 2000:22). In this research study an AIDS orphan will be considered as any child under the age of 18 years who has lost either one or both parents through HIV/AIDS.

Children

The constitution of South Africa defines children as being persons under the age of 18 years. Policy makers would agree that children under the age of 18 years should not be expected to be self-supporting (Scofield,

2001:14). For this reason the researcher undertaking this study will consider children to be those persons who are under the age of 18 years.

Loved one

Refers to either grandparent, aunt or uncle.

Registered Nurse

This is an individual authorised to practise and capable of practising nursing or midwifery in his/her right by virtue of registration in terms of section 16 of the Nursing Act, 1978 (Act no. 50 of 1978). Such a person is accountable for evaluating a patient's situation on the basis of knowledge and skill, taking decisions with discretion and acting in accordance with such decisions (South African Nursing Council Terminology List, 1994:30).

Related professionals

These professionals refer to social workers, teachers, school principals, psychologists and Child Protection Team police.

Broad Guidelines

In this study this term will refer to clinical practice guidelines which are systematically developed statements to assist the nursing practitioner and the patient in making decisions about appropriate health care for specific patient needs (Todd, et al, 1998:4).

Partners

These partners refer to trained clinic volunteers, members of health and welfare forums, NGO's (Non-Governmental Organisations), FBO's (Faith-Based Organisa-tions), CBO's (Community-Based Organisations) and NPO's (Non-Profit Organisa-tions).

1.6 PARADIGMATIC PERSPECTIVE

This research study is based upon the nursing theory of WJ Kotzé, An Anthropological Nursing Science: Nursing Accompaniment Theory (Kotzé, 1998:3).

The theoretical grounding of this study is to be found in WJ Kotzé's theory on Nursing Accompaniment (Kotzé, 1998:3-14). Her paradigm perspective provides the foundation against which the experiences of AIDS orphans living in a township will be viewed.

Metaparadigms

For the purpose of this study, there are four metaparadigms requiring explanation in order to understand the specific world of the PHCN caring for AIDS orphans living in a township.

1.6.1 MAN

Man in this study, more specifically the AIDS orphans who are living in the township, is seen as a multidimensional (holistic) being. Kotzé (1998:2) points out that her philosophical and anthological convictions prompt her to see man as being continually concerned with norms, constantly choosing between right and wrong and as an open being, continually changing. The multidimensional, inseparable, body-psyche-spirit is in a continuous dynamic relationship with the surrounding world (both known and unknown), with time, with fellow beings and with God. Within this study man refers to the AIDS orphans living in the township.

1.6.2 WORLD

The term refers to the world in which man exists. The objective or external world is the world of which he is only vaguely aware and of which he has little knowledge. As man explores and gets confronted with certain aspects of his external world, he may get a grip on it; build a relationship with it and so make it part of his "life world". For an AIDS orphan the world of being an AIDS orphan is a new external world. Within this proposed study the AIDS orphans' external world would refer to living in a household in a township without parents or loved one caring for them.

The subjective world or "life world" refers to that part of the world that man has made his own. In this world he knows he is safe, secure and wanted. The subjective world consists of the personal world, interpersonal world, world of co-existence and time. When a child becomes an AIDS orphan his/her subjective world is surrounded by the world of nursing, education and social work. AIDS orphans might find "home" to be daunting and unfamiliar and therefore need accompaniment to adapt to the changes that have occurred in their subjective world (Kotzé, 1998:6).

1.6.3 HEALTH

Kotzé's (1998:12) metatheoretical statement on health is in line with the definition of the WHO (World Health Organisation). It is also seen as a dynamic process in which a person, sick or healthy, must maintain himself as a multi-dimensional being in his relationships, not only in his physical but also in his social environment (Kotzé, 1998:13). Health is thus a relative concept, an adjustment and a process. It has the potential of illness when one is well and wellness when one is ill. The relative concept of illness or wellness is affected by the quality of man's relationship with world, time, fellow-beings and God (Kotzé, 1998:4).

1.6.4 NURSING

According to Kotzé (1998:4), nursing is an interpersonal event, with accompaniment as an integral part of it. Kotzé's theory of Nurses' Accompaniment flows from her philosophical belief based on the premise that nursing is a phenomenon that is only possible on a human level. It occurs between a person in need of help and supportive guidance (ie the accompanied) and the person with the necessary knowledge and skills to provide that support, assistance and guidance (ie the accompanier). In order to be effective, the relationship requires an environment of "trusting, knowledge/under-standing, togetherness" (Kotzé, 1998:10).

Accompaniment is described as a "deliberate, systemic intervention by the nurse to assist the patient/client to overcome the need of help and support, to recovery or self-reliance and the acceptance of responsibility for the purpose of giving meaning in/to personal life even in terminal situations" (Kotzé, 1998:3).

1.7 RESEARCH DESIGN AND METHOD

The research design and method will be briefly outlined in this section of the study. A more detailed discussion will be presented in chapter two of this study.

1.7.1 RESEARCH DESIGN

The design of research details the researchers' overall approach to the research study. With a general understanding of the intent and rationale for conducting a research study the researcher designs a study and formats it following the traditional research approach. Presenting a problem, asking a question, collecting the data, analysing the data and answering the question (Creswell, 1998:18).

This research study will be a qualitative, explorative, descriptive and contextual study based on a phenomenological approach of inquiry: reflecting the experiences of AIDS orphans living in a township. The design will be briefly outlined and discussed in detail in chapter two of this study.

Qualitative research

Qualitative research refers to an inquiry that explores social or human problems and the understanding of how things occur (Creswell, 1994:162). It enables the researcher to build a complex and holistic picture through the analysis of words, to report specific views of the informants and to conduct the study in a natural

setting. According to Burns and Grove (1999:338), qualitative research is a systematic, subjective approach to describe life experiences and give them meaning. A qualitative design will enable the researcher to reveal the complexities of the lives of AIDS orphans living in a township.

Explorative research

A study is exploratory when it tries to uncover relationships and dimensions of a phenomenon by investigating the manner in which the phenomenon manifests itself to any other related areas (Wilson, 1993:90). Grinnell (1993:136) maintains that the definition of exploratory research is that in nature it explores the research question about which little is yet known in order to uncover generalisations, which means the researcher departs from a point of reference "not knowing". The researcher wants to become familiar with children's experiences of living as AIDS orphans living in a township and therefore exploration is needed. The experiences will generate new knowledge which in turn will lead to an improved understanding of those experiences.

Descriptive

The purpose of this design is to explore and describe phenomena in real-life situations (Burns and Grove, 1999:24). Descriptive design refers to the accurate portrayal of particular individuals or real-life situations, for the purpose of discovering new meaning and describing what exists by categorizing the information generated from the study (Creswell, 1994:145). In this proposed study the children's experiences of living as AIDS orphans in a township will be described so that complete and accurate information can be obtained.

Contextual

Context is defined as the particular set of conditions within which the action is taking place (Strauss and Corbin, 1990:96). The context involves situating the object of the study or the phenomenon of a study within its immediate setting (Creswell, 1998:62). Context implies the conditions and situations of an event. It aims at focussing on the specific set of priorities that pertain to a phenomenon. The approach to this study will be contextual. Contextuality will be demonstrated as the study will be carried out in a township in the Nelson Mandela Metropole where children are living as AIDS orphans.

Phenomenology

Phenomenological studies examine human experience through the description that is provided by the people involved. These experiences are called lived experiences. The purpose of this approach is to describe what people experience with regard to some phenomenon and how they interpret it or what meaning the experiences hold for them (Brink, 1996:119). Creswell (1998:13) regards a phenomenological study as a study that describes the meaning that experiences of a phenomenon, topic or concept has for the participants of the selected research study. The lived experiences of children living as AIDS orphans in a township will be described to enable the researcher to have an improved understanding of their experiences.

1.7.2 RESEARCH METHOD

The research method which involves data collection and data analysis can be divided into two phases:

Phase one

Exploration and description of the lived experiences of AIDS orphans in a township.

Phase one consists of a purposive sampling strategy, data collection activities by means of unstructured phenomenological interviews, the researcher's field notes, data analysis according to the descriptive method of Tesch (cited <u>in</u> Creswell, 1998:192) and literature control. This will be comprehensively discussed by the researcher in chapter two of this research study.

Phase two

To provide broad guidelines for Primary Health Care Nurses (PHCN's), related professionals and partners involved in the care of AIDS orphans living in a township.

This phase will entail developing broad guidelines from the data analysis and interpretation as well as the literature control. The information obtained will be used by the researcher to create broad guidelines to assist PHCN's, related professionals and partners involved in the care of AIDS orphans living in a township.

1.8 MEASURES TO ENSURE TRUSTWORTHINESS

Guba's model in Krefting (1991:215) will be used to ensure trustworthiness of the research. Guba identifies four criteria for trustworthiness namely: truth-value, applicability, consistency and neutrality. Truth-value is ensured by using strategies of credibility; applicability by using strategies of transferability; consistency by using strategies of dependability and neutrality by using strategies of conformability. These strategies will be discussed in detail in the following chapter of this research study.

1.9 ETHICAL CONSIDERATIONS

Nurses involved in research studies are responsible for ethical conduct (Chaska, 2001:57). The ethics of Science concern the rights and wrongs in the conduct of research. Because scientific research is a form of human conduct, it follows that such conduct has to conform to generally accepted norms and values (Mouton, 2001:238). Research ethics provide the researcher with a code of moral guidelines on how to conduct research in a morally acceptable way. Such guidelines seek to prevent researchers from engaging

in scientific misconduct, such as distorting and inventing data, plagiarism, failing to maintain confidentiality and privacy of participants, forcing people to be involved in research and not executing the study properly (Struwig and Stead, 2001:66).

The basic ethical considerations to protect the participants from any form of harm that will be maintained throughout this study include:

- Informed consent: Each participant and where possible their legal guardian, will be required to sign a consent form which has been constructed according to the guidelines prescribed by the Human Ethics committee of the University of Port Elizabeth (Now the Nelson Mandela Metropolitan University. See Annexure C and Annexure D).
- v No deception: Participants will be fully informed about the aims of the study, thus avoiding the problems of deception.
- v Right to withdraw (Right to self-determination): Participants will be advised about their right to withdraw from the study
- v Debriefing/full disclosure: Participants will have access to the results of the study and recommendations emanating from the study.
- v Confidentiality: Participants will be assured of the confidential nature of their participation (Annexure C and D).

The principles of beneficence and justice (Polit and Hungler, 1999:130-134)

All of the ethical considerations listed above will be discussed in detail in chapter 2 of this study.

1.10 CHAPTER DIVISION

The research study will be presented in written form with four chapter divisions:

Chapter 1: Overview of the Research Study

Chapter 2: Research Method and Design

Chapter 3: Discussion of Data Analysis and Literature Control

Chapter 4: Guidelines, Recommendations, Limitations and Conclusions

1.11 CONCLUSION

The researcher is responsible and accountable to the truthful voice and the experiences of AIDS orphans living in a township in the Nelson Mandela Metropole in South Africa. The researcher will endeavour to add new meaning to their experiences by developing guidelines for PHCN's, related professionals and partners involved in the care of AIDS orphans living in a township, so as to assist PHCN's, related professionals and partners in answering the cry of the AIDS orphans:

"Please sir, can I have some more?" (Oliver Twist).

CHAPTER 2

RESEARCH METHOD AND DESIGN

"Qualitative research is as an intricate fabric composed of minute threads, many colours, different textures, various blends of material. The fabric is not explained easily or simply. Like the loom upon which the fabric is woven general frameworks hold qualitative research together." (Creswell, 1998:13).

Through the intricate weaving of the fabric, patterns emerge creating a picture in words for the reader to understand what is being explored by the researcher.

2.1 INTRODUCTION

In chapter one of this study the researcher presented an overview of the research study. The research problem was described and the research objectives were defined. This chapter presents a detailed discussion of the research design and method. Data was collected by means of in-depth interviews to assist in the actualisation of the objectives of this research study.

The aim of this study was to provide AIDS orphans with the opportunity to voice the experiences they have had of living in a township following the death of their parents or loved one caring for them, and the impact the experience of living as AIDS orphans in the township has had upon their lives. The experiences they have shared has provided the researcher with a firm basis upon which broad guidelines have been developed for Primary Health Care Nurses (PHCN's), related professionals and partners involved in the care of AIDS orphans living in a township.

2.2 RESEARCH OBJECTIVES

The researcher had a primary and a secondary objective.

- v The primary objective of this study was to describe and explore the lived experiences of AIDS orphans living in a township.
- v The secondary objective of this study was to develop broad guidelines for PHCN's, related professionals and partners involved in the care of AIDS orphans living in a township.

2.3 RESEARCH DESIGN AND METHOD

An overview of the research design and method will now follow:

2.3.1 RESEARCH DESIGN

A research design is a plan for conducting research that maximises control over factors that could hinder the validity of the eventual events (Mouton, 1996:27). In this research study a qualitative, exploratory, descriptive and contextual design with a phenomenological approach to inquiry has been used, reflecting the lived experiences of AIDS orphans living in a township.

2.3.1.1 QUALITATIVE RESEARCH

Qualitative Research "Is an inquiry process of understanding based upon distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex holistic picture, analyses words, reports detailed views of informants and conducts the study in a natural setting" (Creswell, 1998:15).

The researcher chose a qualitative method of inquiry for the following reasons:

- The question proposed was: **What** are the experiences of AIDS orphans living in the township? A qualitative methodology had to be selected because of the nature of the question posed by the researcher. The researcher was not aiming to yield statistical data but rather to tell readers of the study about the lived experiences of AIDS orphans living in the township.
- v The topic needed to be explored because, to date, there were no theories available to explain the lived experiences of AIDS orphans living in a township.
- v The researcher was aiming to present a detailed study regarding the lived experienced of AIDS orphans living in a township.
- The participants could be studied in their natural setting. The AIDS orphans included in this study were all interviewed in their homes in the township where they lived following the death of their parents or loved one caring for them.
- The researcher was interested in "telling the story" of the AIDS orphans in a comprehensive manner.
- The researcher wanted to become an active learner in the research process and be in a position to tell the story of the AIDS orphans in a truthful, informed and honest manner. The researcher

aspired to tell the story of the AIDS orphans from their view and not as an expert looking in and passing judgement on participants (Creswell, 1998:18).

In qualitative research the researcher is not interested in casual laws but in people's perspectives as far as beliefs and personal meaning systems are concerned. By bringing into the equation the perspectives of the participants themselves, issues are viewed in a way that they could not be realised using other techniques (Ritchie, 1999:253). In this research study the researcher provided, through the qualitative research process, a platform from which the AIDS orphans could speak honestly concerning their lived experiences as AIDS orphans in the township.

Through the qualitative research process the researcher was able to obtain data that was thick, rich and complex and gave a holistic description of the participants' subjective experiences (Creswell, 1998:15). Using this approach the researcher of this study was able to create a holistic and truthful picture about how AIDS orphans experienced life following the death of their loved one. The researcher based the research on the realities and the experiences of the AIDS orphans as the researcher went to the homes of the AIDS orphans in the township, listened to their responses and became an active learner, gaining insight through what was being said by the participants.

Qualitative research is also useful in understanding the human experiences of pain and hurt (Burns and Grove, 1999:338). Thus a qualitative approach was used by the researcher to explore and describe the lived experiences of being an AIDS orphan in a township in South Africa.

2.3.1.2 EXPLORATIVE RESEARCH

This type of study is done when there is little known about a certain area of concern or interesting order to uncover relationships and dimensions of a phenomenon by investigating the manner in which the phenomenon manifests itself to any other related areas (Talbot, 1994:90). Grinnell (1993:136) maintains that the definition of exploratory research is that in nature it explores the research question about which little is yet known in order to uncover generalisations, which means the researcher departs from a point of reference "not knowing". By exploring the AIDS orphans' experiences of living in a township, the researcher sought to become familiar with and gain insight and understanding into these experiences. Thus by gaining new knowledge, insight and an improved understanding of those experiences the researcher was able to develop broad guidelines for PHCN's, related professionals and partners involved in the care of AIDS orphans living in a township.

2.3.1.3 DESCRIPTIVE

A descriptive study is designed to explore and describe phenomena in real-life situations (Burns and Grove, 1999:24). Descriptive design refers to the accurate portrayal of particular individuals or real-life situations, for the purpose of discovering new meaning and describing what exists by categorizing the information generated from the study (Creswell, 1998:145). Accordingly the researcher utilized this approach to describe the experiences of AIDS orphans living in a township. The data gathered from this study assisted the researcher in gaining a holistic picture regarding the lived experiences of AIDS orphans living in a township. In accordance with descriptive research the researcher chose to capture the data using an indepth interview method with the participants.

2.3.1.4 CONTEXTUAL

Contextual research involves a particular set of conditions within which the action is taking place (Strauss and Corbin, 1990:96). The context involves situating the object of the study or the phenomenon of a study within its immediate setting (Creswell, 1998:62). Context which implies the conditions and situations of an event, aims at focussing on the specific set of priorities that pertain to a phenomenon. The approach to this study was contextual. Contextuality was demonstrated as the study was undertaken in a township within the Nelson Mandela Metropole, where the AIDS orphans included in this research study lived. Babbie and Mouton (2001:272) explain that it is necessary to understand the participants of the research study against their background of the whole context as this context confers meaning and then the researcher can truly claim to understand the experiences of the participants involved in the research study.

The Demographics of the township where the participants of this study lived are as follows: The population is approximately 112 369 people. Of this population, 38.10% live in informal dwellings, called shacks. A shack is a roughly-assembled hut or cabin made from wood and cardboard with corrugated iron for roofing. In this township the sanitation system of the shacks is a bucket system and the water supply is communal, in the form of a tap with cold running water in the street. The remainder of the population live in formal housing, which is considered to be a house built by the government as part of the Redistribution and Development Programme (RDP) in South Africa. For this reason formal housing is often referred to as RDP housing. These houses are made of concrete breezeblocks and have 2 to 4 rooms. The formal housing has a flushing toilet housed in a small room made of breezeblocks outside the main house. Of these formal homes, 41.34% have piped water inside and 64.69% are without modern day sanitation services. That is to say a communal tap of water in the street services them and their toilet system is a bucket system. When one is considering the supply of electricity, 48.14% of the entire population of this township has electricity; the rest are without electricity. (Port Elizabeth Census, 2002, most recent data available).

2.3.1.5 PHENOMENOLOGICAL APPROACH

Phenomenological studies examine human experience through the description provided by the people involved. These experiences are called lived experiences. The purpose of this approach is to describe what people experience with regard to some phenomenon, how they interpret it or what meaning the experiences hold for them (Brink, 1996:119). Creswell (1998:63) regards a phenomenological study as a study that describes the meaning that experiences of a phenomenon, topic or concept has for the participants of the selected research study. In this research study the researcher focussed on the lived experiences of AIDS orphans living in a township in South Africa. What was of prime importance to the researcher was what could be learnt from the experiences described to the researcher. In undertaking to describe the experiences of the AIDS orphans living in a township, the researcher sought to understand the concepts and themes described by the participants of this study and use what was said to the researcher to develop broad guidelines for PHCN's, related professionals and partners involved in the care of AIDS orphans living in a township.

The success of this study was therefore dependent upon the researcher pursuing a phenomenological approach to the study. Through using this approach the researcher wanted to portray the human side of what the participants were experiencing as living as AIDS orphans in the township and bring the telling of their lived experiences to the fore. The researcher will now discuss the research methodology used in the undertaking of this research study.

2.3.2 RESEARCH METHOD

The research methodology that involves data collection and data analysis, can be divided into two phases. **Phase one** involved the exploration and description of the lived experiences of AIDS orphans living in a township in South Africa. This phase comprised the sampling strategy, data-collection activities, data-collection method, data analysis and literature control. **Phase two** involved the development of broad guidelines for PHCN's, related professionals and partners involved in the care of AIDS orphans living in a township based upon information yielded from the data analysis and literature control of this research study.

2.3.2.1 RESEARCH POPULATION

The research population was children who had been orphaned because their parents or loved one caring for them had died of AIDS or AIDS-related illnesses. The children were living in a township area in the Nelson Mandela Metropole. South Africa.

2.3.2.2 SAMPLING STRATEGY

The researcher used a criterion-based purposive sampling strategy to select participants for this study. Purposive sampling is based on the assumption that the researcher's knowledge about the population can be used to handpick the participants to be included in the sample (Polit and Hungler, 1999:29). Criterion sampling works well when all of the individuals studied represent people who have experienced the phenomenon being studied. This is a critical element of phenomenological studies (Creswell, 1998:119).

In order to participate in this research study the participants had to meet specific criteria. The participants were:

- v either male or female and aged between 12 and 18 years inclusive,
- v living in a township in the Nelson Mandela Metropole, South Africa,
- v all orphaned due to the death of their parent or loved one caring for them from AIDS or AIDS related illness; and
- v AIDS orphans for a minimum of six months. (Six months was considered a suitable time period for the child to have experience of living as an AIDS orphan in a township).

2.3.2.3 DATA-COLLECTION ACTIVITIES

Data-collection is the process of "gathering the information which is needed to address the research problem" (Polit and Hungler, 1999:455). The following table demonstrates the data collection activities of this research study:

Table 2.1 REPRESENTS DATA COLLECTION ACTIVITIES

Data Collection Activities	Phenomenological Tradition	Application to this Research Study
Who is being studied?	Multiple individuals who have experienced the phenomenon.	AIDS orphans living in a township in the Nelson Mandela Metropole, South Africa.
What are the access issues?	Locating the individuals who have experienced the phenomenon.	 V Access was limited to AIDS orphans living in a township in the Nelson Mandela Metropole, South Africa. V Owing to the in-depth nature of the study, it was convenient for the researcher to interview AIDS orphans who were known to the researcher through an already existing Orphan Care Programme in a township within the Nelson Mandela Metropole. V Written permission was obtained from all of the orphans and guardians (where available) who were willing to share their experiences of living as AIDS orphans in a township.

Data Collection Activities	Phenomenological Tradition	Application to this Research Study
How were individuals selected for this study?	Locating individuals who had experienced the phenomenon - a criterion sample.	v Criterion Sampling was the most successful as all the individuals participating represented people who had experienced the phenomenon. Only AIDS orphans living in a township met the specific criteria and were interviewed. v Specific sampling criteria was formulated (Section 2.3.2.1).
What type of information was typically collected?	In-depth interviews were conducted and data saturation determined the size of the sample.	The researcher collected data until saturation had occurred ie where new data collected no longer gave further insights into the phenomenon of living as an AIDS orphan in a township.
How was information obtained?	Well described interview protocol. The goal of the researcher was to obtain information and insight into the issues relevant to the general aims and specific questions of the research study.	 The process of information collection mainly involved in-depth interviews to ensure that the experiences of the group of AIDS orphans living in a township in South Africa were described in detail. Each interview was no longer than one hour and 15 minutes in duration. Each interview was audio taped and transcribed verbatim. The researcher made field notes following every interview so as to keep a detailed record of all that had occurred during the interview.
What were the common data collection issues?	Bracketing one's experience. Creswell (1998:235) states that bracketing is the first step in phenomenological reduction; the process of data analysis in which the researcher sets aside, as well as possible, any preconceived experiences relating to the participants in the study.	v The researcher as a person was magnified in the process, because the interviewer herself was the main instrument in obtaining knowledge. v The researcher put aside personal knowledge and experience regarding the previous interactions with AIDS orphans living in a township.
How was data analysed? How was information stored?	v Transcriptions v Cassette tapes v Computer files	The researcher used Tesch's data analysis method (cited Creswell, 1994:155).

2.3.2.4 DATA COLLECTION METHOD

"The qualitative research interview attempts to understand the world from the subject's point of view, to unfold the meaning of people's experiences, to uncover their lived world prior to scientific explanations."

(Kvale, 1996:1).

The researcher made use of unstructured phenomenological in-depth interviews as a means of data collection. According to Crabtree and Miller (1999:193), an in-depth interview is a particular field research data-gathering process designed to generate narratives that focus on specific research questions. In-depth interviews are personal and intimate, with emphasis on depth, detail, vividness (intensity) and nuance (subtle difference in meaning). The researcher therefore conducted such interviews with children living as AIDS orphans in a township so that their lived experiences could be used to develop guidelines for PHCN's, related professionals and partners involved in the care of AIDS orphans living in a township.

Such a qualitative research situation is indeterminate and cannot be controlled as in conventional research methods. The researcher therefore had to rely upon techniques such as interviews and non-verbal cues (Papaikonomou, 2004:287). Participants were informed about the purpose of the research study as well as the possible benefits and outcomes of the study. Written consent was then obtained from each participant included in this study and legal guardian where possible (see Annexure C and D).

A pre-determined, general opening question was posed to each participant. They were all given the opportunity and encouraged to discuss issues beyond the confines of the question posed by the researcher (Struwig and Stead, 2001:98).

The following question was the question the researcher posed to each participant of this study.

"Can you tell me about your experiences of living as an orphan in a township?"

The opening question yielded spontaneous and rich descriptions of the phenomenon being studied. The remainder of the interview proceeded as following up of dimensions introduced in the stories told in response to the initial question. Data was gathered from each interview until new data no longer gave new insights; thus the data became "saturated" (Smith, 1999:107).

2.3.2.5 THE ROLE OF THE RESEARCHER

The researcher became the research instrument and had to make quick choices continually about how and what to ask the participants (Kvale, 1996:147). The researcher had to have an open manner, remain gentle and sensitive and had to have an ability to steer the participants to answer the question posed and be willing to examine new ideas posed by the participants of the research study (Burns and Grove, 1999:80). The researcher listened to the AIDS orphans' stories about living as AIDS orphans in a township and sought to be interested, attentive and caring about what was shared by the participants. The participants were encouraged to share whatever they wanted to regarding their experiences as living as an AIDS orphan in a township. The researcher sought to maximise the opportunities for the AIDS orphans to tell of their experiences, so as to produce rich data that was meaningful and informative for data analysis.

According to Burns and Grove (1999:428) the quality of the data collected depends upon the quality of the interviews and observations made by the researcher. The researcher of this study sought to establish a rapport with each participant of this research study, based upon respect, trust, care and empathy. This was considered of prime importance to the researcher, and establishes a firm foundation upon which rich data was collected.

To be an effective qualitative researcher, sound communication is essential. The researcher needed to have excellent communication skills to ensure high-quality interviews. A discussion of these communication skills will now be given.

2.3.2.6 COMMUNICATION SKILLS

"A conversation is a process of two people understanding each other. Thus it is characteristic of every true conversation that each opens himself to the other person, truly accepts his point is worthy of consideration and gets inside the other to such an extent that he understands not a particular individual but what he says" (Kvale, 1996:21).

Without conversation between two people there would be no interview. The key to success in any conversation is the ability to communicate. Thus in order for the researcher to conduct successful interviews with the participants, the researcher required excellent communication skills. In order to encourage the participants to relate their experiences to the researcher, the researcher used non-directive communication skills:

- Probing: This technique refers to the ability of the researcher to explore in depth that which is being explained by the participant. This ability enables the researcher to assist the participant in explaining fully the experiences they have had and feelings associated with those experiences. Examples of such questions and/or statements which were used by the researcher: were: Can you tell me more about how that made you feel? Can you tell me more about that? Is there anything else that you would like to say?
- Summarizing: The researcher summarised at the end of each interview what was said by the participant. This was done to highlight key points that were identified during the interview and also to enhance a feeling of progression in communication. It also created a sense of movement in exploring ideas and findings (Okun, 1992:25).

- Silence: This refers to the permissive pause that gives control to the participants and enhances spontaneity by creating a space for expression by the participants, by indicating respect for what has been spoken. It also allowed the participants time to formulate their thoughts and feelings. The researcher was acutely aware that for all of the participants included in this study it was their first occasion to speak openly about their experiences as being an AIDS orphan in a township. Silence was a necessity in the interview process as it created a space for extended disclosure by the participants (Kvale, 1996:134-135).
- Reflecting: The researcher used reflecting by repeating what the participant had said in order to clarify that what had been said by the participant and to give validity to what had been shared by the participant (Kvale, 1996:20).
- Clarifying: This was the attempt by the researcher to focus on and understand the basic nature of what had been shared by the participant. The researcher asked for clarification when both she and the participant were unable to understand what had been said, thus bringing into focus for both the researcher and the participant what has been explained by the participant. For example, the researcher used statements such as: Do I understand you correctly in that you feel ...?
- Responsive listening: The researcher demonstrated responsive listening to the participant in order to demonstrate awareness to the participant that the researcher was aware of their non-verbal communication: eye contact, body posture, gestures and facial expression. This implied to the participant general understanding, acceptance and concern by the researcher as to what was being said.
- Minimal verbal responses: The researcher adopted a less active role in the interview so as to indicate to the participant that the researcher was listening to what was being said. The researcher made some gestures such as nodding head, raising an eyebrow or leaning towards the participant when they were speaking, making affirming noises such as "mmm, "uhhh" and "ok, can you continue?"

Following the completion of all the interviews that were conducted in this study, the researcher felt the data was rich and gave insight into the question posed. The researcher's questions were few and short whilst the responses of the participants were long and spontaneous (see Annexure E: Copy of transcribed interview from this research study).

The audio-tapes were numbered and corresponded to the biographical detail and field notes. The tapes were then ready to be transcribed and thereafter sent for independent coding.

2.3.2.7 THE INTERVIEWS

Now that the main question has been posed and the floating prompts have been discussed, the researcher will discuss "setting the scene". According to Crabtree and Miller (1999:99), staging the scene consists of four sections. They are: setting the stage, learning the part, equipment checking and performing a pilot interview.

- Setting the stage: The researcher identified the AIDS orphans included in this research study through an existing orphan care programme. The researcher met the AIDS orphans at one of their regular support group meetings and identified those to be included in this study. The researcher thus made initial pre-interview contact with each participant to set up the details of the interview. The following steps were taken by the researcher:
 - The researcher made contact with each of the potential participants and their guardians (where possible) before the commencement of this research study.
 - The researcher explained to all the participants the objective of the research study and invited the AIDS orphans to participate in the study.
 - The researcher obtained consent from the participants and, where possible, their legal guardians before any interviews were conducted to ensure protection of the participants.
 - The researcher interviewed the participants in their individual homes at a predetermined time and date convenient for both the researcher and participant.
 - The researcher reduced disturbance to a minimum by the shutting the door after entering the
 - The researcher informed the participants about the use of the audio-tape recorder and notetaking. The AIDS orphans were made fully aware by the researcher of the reason for their use.
 - The researcher notified each participant regarding the length of the interview and reassured the participant that confidentiality and anonymity would be maintained.
- v **Learning the part**: This refers to knowing as much as is possible about the local setting and the participants themselves.
 - The researcher had worked with AIDS orphans in the township for two-and-a-half years previous to the commencement of this research study and had worked for two years as a Primary Health Care Nurse in various townships clinics within the Nelson Mandela Metropole.
 - The researcher had become familiar with the context of the research study through managing a project for widows and AIDS orphans living in townships in the Nelson Mandela Metropole.
 - The researcher had undertaken a cultural module, specifically studying the Xhosa culture, and so had insight into the culture and cultural practices of the participants of this study.

- The researcher speaks some Xhosa and was able to converse with the participants of this research study in their own language.
- At the time of writing this research study the researcher has been working with AIDS orphans in the township for four-and-a-half-years.
- v **Equipment checking:** Prior to the commencement of each interview the researcher ensured the following:
 - The environment was conducive for conducting the interview, namely quiet, private, familiar to the participant, at a comfortable temperature and free from interruptions.
 - The dictaphone was working and the researcher carried extra tapes and spare new batteries.
 It is important when using audiotape to test the equipment in order to make certain it will record the voices of the researcher and participants correctly.
 - The researcher made every effort to avoid losing data and to ensure a high-quality recording of each interview. A pilot interview was conducted as a measure to avoid losing data and to test all aspects of the recording equipment.
- Pilot Interview: A pilot interview was conducted with one of the AIDS orphans particularly identified for this research study, to assess if the sequence and wording of the questions posed were understandable to the participants and within the framework of a phenomenological approach to inquiry. This also served as an assessment tool for the researcher related to the technique of interviewing (Compare Crabtree and Miller, 1999:101).
- The interview: The interview was conducted after staging the scene. The interview process required the researcher to take note of her attitude before and on engaging in the interview with the participant. Throughout the interview the researcher was aware of the following aspects:
 - The researcher was able to put the participant at ease by being punctual for the appointment, bringing refreshments in the form of a warm chocolate drink and biscuits, chatting generally to "break the ice" and reassuring the participant regarding the right to confidentiality and anonymity.
 - The researcher did her best to display the communication skills already outlined in section 2.3.2.5 of this chapter. She sought to display an attitude of confidence and openness to ensure the participants felt secure and in an environment where they could share their experiences openly and safely.
 - The researcher was sensitive to any changes in the type of communication, especially during sensitive stages when the participants revealed information regarding their experiences which caused them to cry. In this instance the researcher allowed the participant space to cry and time to regain composure, called "toning down" (Crabtree and Miller, 1999:97).

- The researcher remained attentive and constantly evaluated the material of the ongoing interview. The researcher was aware of the constant need to bracket what was being shared so as not to add bias and to avoid miss interpretation of what was being said.
- v **Post interview evaluation:** Following the official end of the interview the researcher turned off the Dictaphone and engaged in "social chit chat" with the participant for a further 15-20 minutes. This time served to:
 - assess how the interview went.
 - assess how the participant was and if there was need for a referral for debriefing or counselling session. The researcher was aware that for all of the participants involved in this research study it was their first occasion of speaking openly regarding their experiences. The researcher was aware that verbalising these experiences could have been traumatic, as many negative emotional experiences were recounted and verbalised by the participant and then,
 - thanked the participants for their contribution in the study and the valuable contribution they
 had made to the study through their participation.

Throughout this study the researcher kept field notes. These types of notes and the rationale for their use will now be discussed.

2.3.2.8 FIELD NOTES

These were kept by the researcher and consisted of everything the researcher was exposed to during the research study. Field notes were therefore included as a chronological description of what happened during the research study (Wilson, 1993:222). The field notes provided a system whereby the researcher could remember observations that were made throughout the duration of the research study. They were written by the researcher as soon as was possible following the interview, and form the main source of information when collecting and analysing field data. The following types of field notes were used by the researcher in this study:

Observational notes are descriptions of events experienced through watching and listening. They contain the who, what, where and how of a situation and contain as little interpretation as possible (Wilson, 1993:224). Observation and interviews are important and go together, allowing for a thorough understanding of what is being studied. Observations of the participants behaviour are one of the most important ways in which changes in the problem can be evaluated. Behaviour was observed in the following forms: regularity, duration, interval and intensity (De Vos,

2002:286). In this study observation notes reflected the events as they occurred during the interview, particularly the non-verbal communication of the participants.

- Theoretical notes refer to the self conscious, systematic attempts made by the researcher to derive meaning from the observational notes. The observer, as recorded, thinks about what he/she has experienced and makes whatever private declaration of meaning he/she feels will bear conceptual fruit. From the theoretical notes the researcher was able to identify patterns that were repeatedly found in the course of the study. The researcher explained the phenomenon under review with the models found in the relevant literature (De Vos, 2002:287).
- Personal notes are the researcher's own reactions, reflections and experiences (Wilson, 1993:223). Personal notes require introspection and putting oneself in the other person's shoes. The researcher used a reflective diary and wrote down her experiences following each interview eg "I felt sad that a child had to suffer so much because of lack of care and support." Throughout this study the researcher kept personal notes and was able to gain deepened understanding of the participant's experiences of life living as AIDS orphans in a township.

2.3.2.9 ANALYSIS OF DATA

Data was analysed using Tesch's method, as described in Creswell (1994:153). Identified themes were then formulated. A consensus discussion between the independent coder and researcher took place to finalise the themes identified (Krefting, 1991:216, Creswell, 1994:158). Tesch's approach proposes eight steps to engage a researcher in a systemic process of analysing data:

- 1. The researcher read through the whole document to get a sense of the whole story.
- 2. The researcher selected one interview and asked the question: What is this all about?
- 3. When the researcher had completed this for several respondents she made a list of all the topics isolated.
- 4. The researcher then used that list when returning to the data for further analysis. The topics were then given codes, which were written next to the appropriate segments in the text. The researcher then organised the topics into categories; and then returned to the data to see if new topics had emerged.
- 5. Through descriptive wording for the topics the researcher turned the topics into new categories showing interrelationships between the categories further reduced category groups.
- 6. The researcher then made a final decision on the abbreviations and alphabetised the categories.
- 7. Data belonging to each category was then assembled in one place and preliminary analysis was performed.

8. A set of clean data was then given to an independent coder who has experience in qualitative data analysis.

The independent coder was then asked by the researcher to assist in the identification of the themes. On completion of this the researcher, independent coder and the researcher promoter, had two meetings to reach consensus concerning the identified themes. Both the researcher and the independent coder agreed that data had been saturated and there was therefore no need for further interviews.

The researcher agreed (following the second meeting) that the categories, themes and sub-themes portrayed in a meaningful and descriptive way what had been expressed by the participants.

2.3.2.10 LITERATURE CONTROL

After data analysis, a literature control was implemented to compare findings of the study and to determine similarities and differences from the existing data in literature (Compare Streubert and Carpenter, 1995:46).

2.3.2.11 PHASE TWO

The information obtained from the data analysis and literature control was used to formulate broad guidelines for PHCN's, related professionals and partners involved in the care of AIDS orphans living in a township.

2.4 MEASURES TO ENSURE TRUSTWORTHINESS

Trustworthiness is described as "a term used in the evaluation of qualitative data, assessed via criteria of credibility, transferability, dependability and conformability" (Polit and Hungler, 1999:470). Guba's model in Krefting (1991:215) was used to ensure trustworthiness in this research study. Guba's model consists of the following four criteria:

v Truth-value

Truth-value asks whether the researcher has established confidence in the truth of the findings for the subjects and the context in which the study was undertaken. It establishes how confident the researcher is with the truth of the findings based upon the research design, informants and contexts. In qualitative research, truth-value is usually obtained from the discovery of human experiences as they are lived and

perceived by informants (Krefting, 1991:215). Specific strategies can be used throughout the research process to increase the worth of qualitative projects. Strategies to ensure credibility include prolonged and varied field experience, reflexitivity and triangulation, peer examination, interviewing techniques, structural coherence and the authority of the researcher.

v Applicability

Applicability is the ability to generalise from the findings to larger populations than those tested in this research study (Krefting, 1991:216). Lincoln and Guba, 1985 (in Polit and Hungler, 1999:307) refer to transferability as the generalisability of the data i.e. the extent to which the findings of the data can be transferred to other groups or settings.

v Consistency

Consistency refers to whether findings would be consistent if the enquiry were replicated with the same subjects or in similar context (Krefting, 1991:216). In qualitative research it is acknowledged that it is difficult to expect consistent results if a study is replicated, even if the same participants or similar contexts are used. The reason is that the participants, the researcher and the specific circumstances of the study can vary greatly within the research. Guba (in De Vos, 1998:351) states that the criterion for consistency is dependability. This refers to the attempt by the researcher to account for these changing conditions to the phenomenon chosen for the research and the changes in the design. The measures to ensure dependability include code-recode procedure, dense description of research methods, triangulation and peer examination.

∨ Neutrality

Neutrality refers to the degree to which the findings are a function solely of the informants and the conditions of the research and not other biases, motivations or perceptions (Krefting 1991:216). Guba 1985 (in De Vos, 1998:315), states that confirmability is the criterion against which neutrality is measured. This refers to whether the results of the research could be confirmed by another research study and places the evaluation on the data itself. The application of conformability strategies which are triangulation and reflexivity are set out in the following table

Table 2.2 STRATEGIES TO ENSURE TRUSTWORTHINESS

CRITERION TO ENSURE TRUSTWORTHINESS	STRATEGY	CRITERON	APPLICABILITY
TRUTH VALUE	Credibility	Prolonged engagement	The researcher has been involved in working with AIDS orphans in Africa since 1993 and specifically in South Africa since 1998. During the last four years the researcher has been working exclusively with widows and AIDS orphans in

CRITERION TO			
ENSURE TRUSTWORTHINESS	STRATEGY	CRITERON	APPLICABILITY
			townships in the Nelson Mandela Metropole, South Africa. Contact was made with the participants prior to the interviews to establish rapport with them.
		Reflexitivity	The researcher made use of field notes throughout the research process. These notes reflected the researcher's thoughts, feelings and ideas within the research context. The researcher became aware of preconceived ideas and assumptions whilst writing these notes, and was thus able to maintain objectivity.
		Triangulation	Data was collected through field notes and personal journals. Data was confirmed through literature control. The researcher and an independent coder analysed the data from the interviews. Participants interviewed were of different ages and also different genders. Two supervisors, both experienced in the fields of qualitative research, were used to decrease any bias. Literature control was carried out through the use of journals, books, newspaper articles and internet searches.
		Peer examination	The researcher held informal discussions with AIDS orphan care workers in the township. The researcher visited an orphan care programme in Johannesburg and met the director of that organisation. The researcher used research experts in the discipline of qualitative research and an experienced independent coder. Consensus was reached by the independent coder and researcher regarding the emergent themes from the data.
		Interviewing techniques	In-depth interviews with a phenomenological approach were conducted. The same open-ended question was posed to all the participants, to determine the presence of logical rationale. The researcher followed all the steps in conducting in-depth interviews to the best of her ability. Communication skills verbal and non-verbal were used to en-

CRITERION TO ENSURE TRUSTWORTHINESS	STRATEGY	CRITERON	APPLICABILITY
			courage participants to talk freely. A pilot interview was conducted to enhance interviewing skills.
		Structural co- herence	The participants experiences of living as AIDS orphans in a township were the focus of this study. The researcher, research promoter and co-supervisor ensured that there were no inconsistencies between the data and interpretation thereof.
		Authority of the research- er	The researcher, having worked in the townships with AIDS orphans, was familiar with the phenomenon being studied. The researcher was advised by supervisors with extensive experience in conducting qualitative research.
Applicability	Transferabi- lity	Nominated sample	A purposive criterion based sample was drawn up from the available participants. The researcher set sample criteria
		Dense des- cription	(see section 2.3.2.2). A complete description of the research method and design (including the literature control) was given to establish clarity. The dense description has been written in such a way that another researcher would be able to follow the proceedings of this study.
Consistency	Dependabili- ty	Dense description	The research design and methodology was fully discussed.
		Triangulation	The researcher has combined transcribed interviews, personal journals and the researcher's notes in the data collection process.
		Peer exami- nation	Independent checking was carried out by experienced colleagues in the field of research.
Neutrality	Confirmabili- ty	Confirmability Audit	An experienced independent coder was used in the analysis of the data.
		Triangulation and Reflexivity	Data was collected and analysed by means of transcribed interviews, a personal journal and field notes as already discussed.

The table above was adapted from Krefting (1991:214).

2.5 ETHICAL CONSIDERATIONS

Nurses involved in research studies are responsible for ethical conduct (Chaska, 2001:57). The researcher assured that all participants in this study had the right to equity, justice, human dignity, life and protection against harm, informed consent, confidentiality and anonymity.

The research study was planned and executed in such a way as to foster beneficence and to exclude harm and exploitation of the children. Every effort was made by the researcher to ensure that no harm was done to the vulnerable group of children who had already been exposed to emotional trauma. The children participating in this study were assured that they could discontinue participation in the study at any time if it was too distressing for them.

v No harm to participants

An ethical researcher must be prepared, at any time during the research, to terminate the research if there is reason to suspect that continuation would result in undue stress to the participants. It was considered by the researcher that this was possibly the first opportunity that the AIDS orphans would have had to verbalise their thoughts and feelings concerning their lived experiences as AIDS orphans living in a township. Participants were reassured that they could withdraw at any time from the study if it was too emotionally distressing for them to continue. The researcher considered the wording of the questions carefully and offered debriefing sessions and any referrals which were considered necessary to uphold the ethical principle of "no harm". This was done to ensure that this vulnerable group of participants were not exposed to psychological harm (Polit and Hungler, 1999:130).

v Freedom from exploitation

Involvement in a research study should not place participants at a disadvantage or expose them to situations for which they have not been explicitly prepared (Polit and Hungler, 1999:130). The entire research process was explained to the participants. The researcher was aware that the participants were possibly feeling fearful about expressing their feelings, as they were to become vulnerable when disclosing their experiences of living as AIDS orphans in a township. The researcher reassured the participants that the sensitive information that they shared with the researcher would not be used against them in any way and that the information shared would not be divulged to others in their family or community.

v Right to self-determination

The principle of self-determination was adhered to throughout this study. That meant that the participants had the right to decide voluntarily whether to participate in the study without the risk of incurring any penalties or prejudicial treatment. It also meant that the participants had the right to refuse to give

information and could also ask for clarification regarding the purpose of the study or specific questions (Polit and Hungler, 1999:133).

v Informed consent for children under the age of 18 years

Legal age of consent differs between countries. Article 1 of the declaration of Helsinki (World Medical Association1996 in Smith 1999:174) states that "In the case of legal incompetence, informed consent should be obtained from the legal guardian in accordance with national legislation ... where subject is a minor, permission from a responsible relative replaces that of the subject in accordance with national legalisation. Whenever the minor child is in fact able to give informed consent, the minor's consent must be obtained in addition to the consent of the minor guardian."

The constitution of South Africa Act (1996) and the Child Care Act of 1996 (as amended), defines the child as a person under the age of 18 years. The amended Child Care Act distinguishes between the ages of 14 years and 18 years for legal consent but the parent or guardian retains the right to give consent. **However, the parent's consent should not override the child's consent.** For example, in the case of the choice of giving consent, a 14-year-old female may give consent to the termination of pregnancy procedure. The law agrees and stipulates that the child must demonstrate the ability to give informed consent and has the capacity to do so. In other words the child must demonstrate the ability to show an understanding of the potential consequences, risks and the benefits of the termination of pregnancy. Then upon meeting the specific conditions, such as understanding of the termination of pregnancy procedure, a minor of 14 years can sign a consent form (Kunins, 1993:205-215). For this reason all of the AIDS orphans selected to participate in this study signed their own consent forms.

Older children who are capable of providing informed consent should normally be chosen in preference to younger ones (Smith, 1999:18). The Department of Health (in Smith, 1999:180) shares and supports this view that any research involving children is important for the benefit of all children and should be encouraged, but constituted in an ethical manner, as long as it carries minimal risk. In this study the researcher followed a criterion-based purposive sampling procedure and approached the legal guardian and the participant to obtain consent. The researcher thoroughly explained that the study was designed to benefit AIDS orphans living in a township. The aim was to make recommendations to Primary Heath Care Nurses, related professionals and partners involved in the care of AIDS orphans living in a township. An explanation by the researcher was made both verbally and in writing (see Annexure C and D). The researcher took into account stage of the child's development and the child's degree of understanding of the nature of the research when obtaining consent. It was thus necessary for the researcher to inform the child fully about the study in the language and terms that the children could understand. It was decided by the researcher prior to the study that if a child (between the ages of 12 and 18 years) was insufficiently mature to

give consent and unable to comprehend the information given to him or her, that that child would be excluded from the study. Thus the validity of consent was therefore dependent on the child's understanding and intelligence (Grubb, 1997:11-17). No pressure was exerted on the children or guardian by making them to feel guilty if they did not wish to participate in the study. The researcher gave the child and the guardian enough time to decide whether or not to participate in the study. The researcher also explained that if the AIDS orphans participating in the study felt too uncomfortable and/or distressed, they would tell the researcher and the researcher would terminate the interview. The researcher respected that the decision to be involved in her study was solely that of participants and not the researcher. The children participating in the study were given food to eat before the interview was conducted, namely bread, eggs, peanut butter, fruit and milk to drink.

CIOMS/WHO (1993:5) state that researchers must be available to respond to the participant's questions and concerns through out the study. Furthermore they indicate that the guardian must be encouraged to stay with the child during the research so they can withdraw their child if they consider it to be in the best interests of their child to do so. The researcher constantly monitored the child for signs of stress and anxiety that might have necessitated the withdrawal of the child from the study. In order for informed consent to be valid, according to the WHO guidelines (CIOMS/WHO, 1993:3), the researcher has a duty to:

- v communicate to all the prospective research participants all the information necessary for adequate informed consent.
- v provide and encourage the participant full opportunity to pose questions.
- v exclude the possibility of unjust deception, undue influence and intimidation.
- v seek consent only after the participant has sufficient knowledge of the relevant facts and of the consequence of participation, and had adequate time to consider whether to participate.
- v obtain from each participant a signed evidence of consent.

Both the guardians and the children were informed that they were unlikely to benefit directly from participation in the research study and that the goal of the research study was to make recommendations to primary heath care nurses, related professionals and partners involved in the care of AIDS orphans living in a township. The researcher informed the participants that their contribution was important in helping other AIDS orphans living in a township and that, in this way, they were directly helping others and making a difference.

The researcher informed all of the AIDS orphans and guardians participating in this study that their participation was entirely voluntary. The right to self-determination, which means that participation is to be informed and that he/she is free to withdraw from the study at any time, was upheld and adhered to by the researcher. The researcher stated to all participants included in this study that they could refuse to participate or withdraw from this study at any stage even after they and their guardian had signed consent.

v Privacy

Privacy according to Brink (1996:40) privacy is the freedom an individual has to determine the extent and general circumstances under which private information will be shared with, or withheld from, others. Individuals who agree to participate have a right to expect that the information collected from them would remain private between the researcher and the participant. This was upheld through principles of anonymity and confidentiality.

Confidentiality and Anonymity

Confidentiality refers to the researcher's responsibility to protect all the data gathered within the scope of the project from being divulged or made available to any other persons. This meant that the researcher did in means share the data from the interviews with outsiders. The participants were assured by the researcher that information they shared with the researcher would not be shared with doctors, nurses or family members. Research data was kept closed and only persons involved in the research study had access to it. This was unless the participant gave the researcher explicit permission to make the data known. The participants were told before they consented to participate in the study that the researcher would be publishing the findings of the study. The participants were informed that the researcher would do her best to ensure that personal characteristics would not be made known. A breach of confidentiality can occur when a researcher allows an unauthorised person to gain access to the raw data of the study, or when the researcher accidentally or otherwise reveals the participants identity in the reporting of the research (Brink, 1996:40). This was not the case in this research study. The researcher as far (as was humanly possible) maintained confidentiality.

v Anonymity

This refers to the act of keeping the individuals nameless in relation to their participation in the research. No one including the researcher was able to link specific data to a specific person in the township (compare Brink, 1996:41). In order to ensure anonymity for the participants the researcher utilised the following mechanisms as outlined in Brink (1996:4) ie providing each participant with a number or code name, keeping the master list of participants and matching code numbers in separate locations, destroying the list of actual names, use code names when discussing the data and having participants generate their own identification code if preferred. Audio-tapes were kept in a safe place and destroyed after the research. It was important to ensure anonymity to those participating in this study so that the children felt free to express their thoughts and ideas. Privacy was thus ensured by the researcher upholding these ethical principles thought the research study.

v Debriefing

Debriefing sessions were held after the research, during which the participants had the opportunity to work through their experiences and the aftermath thereof. These sessions had the purpose of rectifying any misinterpretation which may have arisen in the minds of the children after the completion of the research. The research involved a very sensitive and possibly painful recall of experiences; so the researcher felt

obligated to make some intervention in the form of referrals to some of the participants involved in this research study and provide a follow up supportive referral source for each of the respondents who needed to be helped in this manner. Denzin (1994:45) contends that debriefing sessions are the most important time to complete the learning experience that started with the consent to participate in the research study.

v Action and competence of the researcher

The researcher based her research on a scientific principles and sought to be as non judgemental and objective as possible (Denzin, 1994:54). The researcher was guided by the ethical standards for nurse researchers to ensure she was skilled and competent as stated in South African Society for Nurse Researchers (1996:74). The researcher worked according to the research proposal under the guidance and mentorship of distinguished researchers appointed by the University of Port Elizabeth (now the Nelson Mandela Metropolitan University). The identification, affiliation and qualifications of the researcher were made known to the participants of this study.

The researcher acknowledges the right of the community and the Science community to quality research, which was ensured by the researcher. The researcher adhered to the highest standards of research planning, implementing and reporting. All efforts by the researcher were made to remain neutral and unbiased throughout the study through the "bracketing" her own views, beliefs and experiences. The research was performed honestly and no evidence was manipulated. Conclusions have been justified and findings have been fully reported. All inputs from the AIDS orphans have been acknowledged. Acceptable procedures and methods of science have been used.

2.6 CONCLUSION

Research involves the planning, execution and interpretation of scientific data (Singleton, 1993:65).

This section on ethical considerations concludes this chapter, which also discussed in detail research design and method utilised to describe the lived experiences of AIDS orphans living in a township. Data analysis was also discussed using Tesch's model as already stated. Measures relating to trustworthiness were also discussed including their application throughout this research study.

In Chapter three the researcher will analyse the data yielded form this study and analyse the results and discuss this in the context of a literature control. The literature control is used to compare the findings of this study with already existing data in literature. This will see the completion of phase one of this research study.

CHAPTER 3

DISCUSSION OF DATA ANALYSIS AND LITERATURE CONTROL

"Please sir can I have some more?" Oliver Twist.

"I decided I would rather go to bed hungry than to continue to beg for food. My mother died of Aids. I cried of a broken heart to think that I was now an Aids orphan" (Mathe, 2003:13).

"Orphans have become the new generation of Oliver Twist, cynical, bitter, and hard to mange" (Hunter, 1990:683).

3.1 INTRODUCTION

"It is difficult to say how terrible my life is since my parents died of AIDS."

The devastation that children experience on being orphaned due to AIDS is at times difficult to articulate. They become hungry, grief-stricken and humiliated. They feel despair, contemplate suicide and experience the physical hardships of extreme hunger and cold. The harshness of rejection and abandonment surrounds their lives and they are sad (Guest, 2001:19). The cry of each one is "Please sir can I have some more?" Their experience of life is harsh; (Green, 2002:2) highlights this in the following words of an AIDS orphan "Sometime back I lost my mother. Before her death, we were struggling, scavenging for discarded food from the rubbish dumps. My mother was the sole breadwinner, but she was earning very little. Sometimes she would send us to beg for food. When she died we had no-one to take care of us. We had no food or soap

and were unable to go to school. We were hungry, left alone and afraid." It is against this backdrop that the results of this study will be considered.

A lived experience does not confront me as something perceived represented; it is not given to me, but the reality of the lived experience is there for me because I possess it immediately as belonging to me in some sense (Max van Mannen, 1990:21).

In this chapter the researcher will analyse and discuss the results of the research material, obtained from the phenomenological in-depth interviews.

3.2 OPERATIONALISING OF DATA ANALYSIS AND LITERATURE CONTROL

Eight in-depth interviews, each lasting approximately one hour, were conducted. Data saturation was reached when no new themes emerged. Data is considered to be saturated when no new information emerges during the process of coding. "It is important to consider that if one looked hard enough one would always find something new. Therefore data saturation is more a matter of reaching the point in the research where the collection of additional data seems counter-productive; the "new" that is uncovered does not add that much more to the explanation at the time" (Strauss and Corbin, 1998:136). Data was considered saturated in this study when eight interviews had been conducted.

The eight participants interviewed all met the inclusion criteria; accordingly they:

- v had all been orphaned for longer than 6 months,
- v were all living in Kwazakhele and neighbouring townships (all within the Nelson Mandela Matrapole),
- v were all between the ages of 14 years and 17 years,
- v were all from the Xhosa cultural group,
- v were all South African citizens,
- v were representative of different gender groups (4 Male and 4 Female),
- v had all lost parents from AIDS or AIDS related symptoms.

The pilot interview was included for data analysis. Interviews were performed according to the explanation presented in the previous chapter. Interviewees were pleased to participate and they were keen to share their experiences of living as AIDS orphans in a township. For all of the participants it was the first time since becoming AIDS orphans that they had spoken openly about their lives as AIDS orphans.

Demographics of a Township

A township is an urban black residential area. The township where this research study was carried out had a population of approximately 112 369 people. See section 1.5 of this study for the most recent data available regarding the demographics of the township where the AIDS orphans in this research study lived.

Independent Coder

An independent coder was appointed to assist with identifying and ensuring trustworthiness of the themes relating to the experiences of AIDS orphans living in a township. The independent coder has also completed a doctoral study programme and has a comprehensive understanding of the qualitative research process. After discussion with the independent coder, supervisor and co-supervisor, it was confirmed that data saturation had been reached. The emergent themes identified by the researcher and independent coder, clearly expressed the stories as told by the AIDS orphans.

Literature Control

The broad aim of the literature control is to place the findings of the research study within the context of the general body of scientific knowledge (Babbie and Mouton, 2001:565). The researcher conducted a literature control in order to:

- v outline what was already known concerning the subject,
- v identify if emergent themes from the research had been previously documented,
- v identify the context in which the research topic was being explored,
- v indicate where the results of this research study, fit into the bigger picture of the general body of scientific knowledge.

3.3 IDENTIFIED THEMES

Throughout research literature, the concept "theme" refers to a subject of a topic or element which occurs frequently within the text (Rogers, 2005:454); Phenomeno-logical themes may be understood as the structures of experience and are the process of insightful invention, discovery and disclosure of meaning (Van Mannen, 1990:79).

Two central themes were clearly identified from all of the research interviews and several sub-themes emerging from the two central themes and have been represented in table 3.1 and table 3.2.

Table 3.1 REPRESENTING THEME ONE AND RELATED SUB-THEMES

MAIN THEMES	SUB-THEMES
1. Children experienced devastating changes	1.1 AIDS orphans verbalised the effect of the
in their life circumstances due to	absence of their parents or loved one in

hasaming AIDC ambana	the home:
becoming AIDS orphans	the home:
	1.1.1 AIDS orphans missed having their
	parents or loved one at home to
	cook, wash and iron their clothes
	1.1.2 AIDS orphans missed their parent or
	loved one to confide in
	1.1.3 AIDS orphans missed having their
	parent or loved one to express care
	on their special days
	1.1.4 AIDS orphans missed a sense of
	belonging
	1.1.5 AIDS orphans became overwhelmed
	by a lack of finances
	1.2 AIDS orphans engaged in harmful
	activities to alleviate the effects of the
	devastation they experienced:
	a) criminal behaviour,
	b) prostitution,
	c) smoking dagga and
	d) alcoholism.
	1.3 AIDS orphans verbalised feelings of
	being:
	a distressed
	b helpless
	c abandoned
	d lonely
	e grief-stricken
	f neglected
	a angry
	b rejected
	a overwhelmed
	b fearful
	c uncertain
	d suicidal
	a glad, joyful, loved, hopeful

Table 3.2 REPRESENTING THEME TWO AND RELATED SUB-THEMES

THEME	SUB-THEMES

2.	AIDS orphans rediscovered hope to go on living.	2.1	AIDS orphans relied on the following relationships to re-establish hope: 2.1.1 friends/boyfriends/girlfriends 2.1.2 relatives 2.1.3 God and prayer
		2.2	AIDS orphans experienced the restoration of hope through: 2.2.1 education at school (purpose) 2.2.2 belonging to community groups 2.2.3 community sporting activities

3.4 DISCUSSION OF THEMES AND LITERATURE CONTROL

The AIDS orphans in this research study described their feelings and experiences related to living as AIDS orphans in a township. All of the AIDS orphans involved in this study said it was the first time they had been asked to talk about their lives since they had become AIDS orphans. The AIDS orphans' experiences have been represented in two themes with sub-themes. The results and related literature will be discussed in a narrative form. Two central themes and sub-themes which were identified will be presented, discussed and supported by relevant quotations from the interviews. Reference to existing literature has been made throughout the discussions in this chapter in order to place the research findings within the context of the general body of scientific knowledge (Babbie & Mouton, 2001:565). The researcher will write in blue the data presented from the interviews included in this study. Quotes made from the general body of scientific knowledge will be presented in red; this is for the sake of clarity in presenting the results of this study.

The question posed to the participants in this study was:

"Can you tell me about your experiences of life as an orphan in the township?"

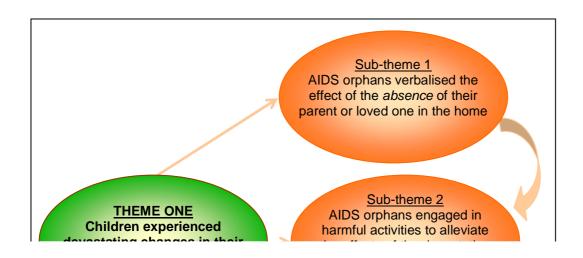


Figure 3.1 DIAGRAMMATIC REPRESENTATIONS OF DEVASTATING CHANGES CHILDREN EXPERIENCED IN THEIR LIFE CIRCUMSTANCES DUE TO BECOMING AIDS ORPHANS

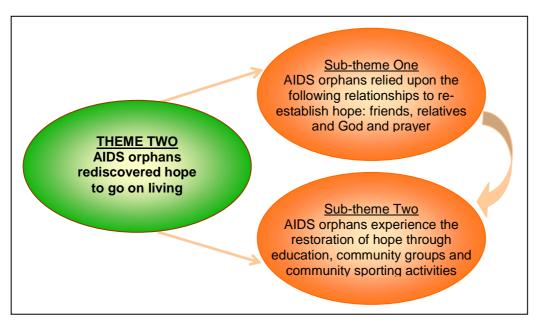


Figure 3.2 DIAGRAMMATIC REPRESENTATION OF HOW AIDS ORPHANS REDISCOVERED HOPE TO GO ON LIVING

3.4.1 THEME ONE: CHILDREN EXPERIENCED DEVASTATING CHANGES IN THEIR LIFE CIRCUMSTANCES DUE TO BECOMING AIDS ORPHANS

At a time in their lives when they should be cared for, the AIDS orphans found them selves discarded because the burden of caring for them in existing family structures was too great. Extended family members who were supposed to care for them were already overburdened by poverty, unemployment and decay in their own family structures because of HIV/AIDS. There was no-one to take them in and care for them. They became bewildered, confused, hurt and found it difficult to describe the enormity of the devastation they experienced. They became like fledglings thrown from the nest, only they were without a safe place to land. They were overwhelmed and devastated by their experiences.

"Since the death of my mother I feel like a piece of rubbish tossed about."

"No-one in my family came to see me I am just now left alone to take care of myself and I don't even know how to make bread."

"Experience" refers to acquiring knowledge and insight following the exposure or personal contact to an event or happening (Rogers, 2005:60).

"Devastation" refers to being laid waste, discarded, and in a state of being overwhelmed (Rogers, 2005:46). Devastation is also referred to as being crushed by, or overpowered by an event, influence or emotion (Oxford English Dictionary, 2004:977)."

"Change" refers to a state of making or becoming different, from the original state. To alter to transform, a state of becoming altered (Rogers, 2005:140). "Life" refers to a state of functional activity (Oxford English Dictionary, 2005:329). A "circumstance" refers to an occurrence a phase or an event that causes an effect, or a happening (Oxford English Dictionary, 2005:154).

"Orphan" in the context of this research thesis will refer to a child who is under 18 years of age, who is living in a home without any parental contact or care by a loved one (eg grandparent, uncle or aunt) due to their death from HIV/AIDS or AIDS related illnesses. The tragedy of AIDS does not end with the sufferer but continues through the lives of the children who are left orphaned. In Africa where the pandemic is at its worst, a whole generation of children are growing up without parents (Guest, 2001:1).

In order to create the backdrop against which the results of this research study can be viewed, the researcher would like to begin with excerpts from the participants' interviews. The following excerpts from the interviews tell of some of the devastation the children experienced, living as AIDS orphans in a township.

"It was too terrible the day my mother died, that day was too terrible to me."

"Now my mother has died its different now. It's too hard to tell you in words (she looks to the floor and cries. The tears roll down her cheeks and fall on the floor)."

"Things in my home are different now that my mother has died. My grandmother was too old for us to take care of her. So she went to be with my aunt. I am sad about this because we did stay nicely with her after my mother died. So it's me and my cousin. We were afraid when this happened to us. No-one came to help us or take care for us. We were worried about how we were going to get food and how would we survive. I was 13 years old when this happened to me. Since that time I take care of myself."

"After my mother died I ran away from home and sleep at Njoli Square. My father was drinking that's why I did leave my home. It was very bad (he looks down at the floor and cries ... long pause) No-one did come to get me. I was just there like that begging for money for bread. I didn't wash; I just slept in a Rainbow chicken cupboard. I had no blanket. I was very cold."

"All I can say is it's like I have a deep pain inside since I became an AIDS orphan I have no words to say how it feels. I have no-one to go to help me. Sometimes I want to die."

"I used to have my own room, when my mother was alive. Since she died I live with my aunt. I sleep in the lounge after everyone else has gone to bed. I pull two chairs together and I sleep like that."

"I feel so low when the neighbours do just give me food and the old clothes of my friends. I hate being poor; sometimes I look terrible. Sometimes people laugh at me; it wasn't like that when my father was alive. Now it's like that. I am sad that we are alone. No-one wants to help us. It is like that. I feel humiliated and I feel sad."

Across the continent of Africa AIDS has left in its wake many AIDS orphans to fend for themselves and assume adult responsibilities at a young age. In South Africa it has been stated that "Orphans living in the township live on the edge of dreadful things. They are oppressed, poor, exploited, humiliated, ashamed and suffering because of the devastation they have come to experience daily" (De Boeck and Honwana, 2005:83). From this place they must somehow cope with the devastation they have experienced. When a child loses his parent to AIDS, he not only loses his parent but his childhood as well. It is this loss of childhood that adds to the devastation of the parental loss and causes the orphans to feel constantly overwhelmed by the devastation of their experience (Loening-Voysey, 2002:105).

3.4.1.1 SUB-THEME 1.1: AIDS ORPHANS VERBALIZED THE AFFECT OF THE ABSENCE OF THEIR PARENT OR LOVED ONE IN THE HOME

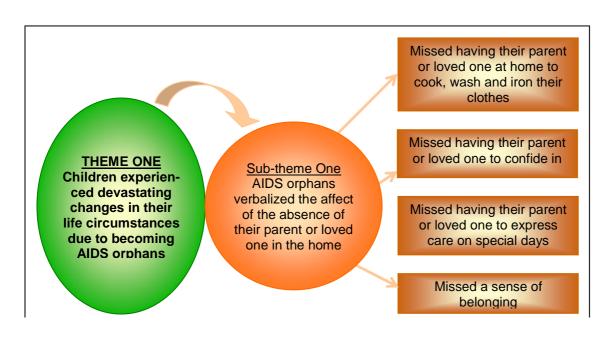




Figure 3.3 DIAGRAMMATIC REPRESENTATION OF HOW AIDS ORPHANS VERBALIZED THE EFFECT OF THE ABSENCE OF THEIR PARENT OR LOVED ONE IN THE HOME

All of the participants included in this study spoke about how they experienced life when their parents were with them in the home. Sengendo, (1997:120) highlights that children who have become orphans experience overwhelming bouts of depression and other negative emotions. Sengendo attributes this to the multiple losses children experience on becoming orphans such as loss of parent, income, siblings, possessions and of schooling. Sengendo further indicates that children experience negative emotions on becoming orphans because they can distinguish between the quality of life they had when their parents were alive and feelings of hopelessness become overwhelming when they consider the loss of their parent and their life as it was before their parents death. Two of the participants said to the researcher when speaking about their parents"I like what you ask because this was a nice time for me. My mother when she was alive was taking very good care of us and we were happy then." One of the participants went on to say" She used to make dumpling for us to eat when we came home from school and warm water every day for us to wash in." Without exception all of the orphans included in this study missed their parents after they had died.

"The thing that affects me the most is the loss of my mother's care. She was always encouraging me and sharing ideas with me. I miss those kind words of encouragement and hope. She was always patient and kind. I miss her meeting me from school."

"When my mother was alive and my brothers were at home I liked being at home with them. We used to help with the cooking and it was a lovely fun time. We just liked to be together. Now I don't like to be home. It's empty and a sad place to me now. Its like the life has gone from my home."

When the researcher visited the home of this particular participant to carry out the interview, she was shown the back room that used to be his mother's bedroom. In the back room were two men from the community sleeping after a drug and alcohol binge. The participant said:

"I don't like that they invade my home. But they are bigger to me and sometimes they do give me something if I do let them to sleep there. So it is like that."

"When my father was alive I always did have hope. He always seemed to get a piece job (casual work) and I was glad because then he did get food and paraffin for us. When he died my hope went. I miss him because he did give me hope."

"By the time my father was alive there were many people staying to my home. It was nice to be together to them all. I loved my father too much because he was kind to me and he takes care of me. When I play outside with my friends he did sit on the bench and watch me. I like him to do that because I feel important then. After he died they all went and my stepmother did also go away. Then I am alone in the house and I did not stay alone before that time. I am scared and lonely. I like to be outside now not in my home. It's cold now and empty."

These statements the children have made are echoed in the literature: "Orphaned children are devastated by the loss of their parent, the consequences of which they feel keenly. It's like a pebble being thrown into the water. The ripples go on and on. The children are devastated by the loss that is compounded by having to take care of themselves. They are ill-equipped to do this and suffer, because of their precarious position" (Foster, 2000:2).

The researcher would also like to comment that none of the AIDS orphans included in this research study expressed relief when they were freed from the responsibility of caring for their parent who was dying of AIDS. The children included in this research study missed their parent greatly when the parent they were caring for died if AIDS or AIDS related illnesses, this is described fully further on in this chapter.

"I used to do everything for my mother. I would collect her money from the bank, look after her when she was sick, I used to wash her and help her go to the toilet. I used to lift her from the bed to a bucket so she could go to the toilet. Then go and empty it. I used to do all the washing and I used to also wash my mother. She used to sleep on my bed with me. I like that. I miss her being here with us."

"My father was just coughing all the time. My sister and I did care for him. She washed his top and I did wash the bottom parts. I take him to the toilet because he is too weak. My sister she did wash him and feed him. I did do all of the cleaning of the house and yard. I used to buy from the chemist rubbing stuff for his chest. I used to rub it for him and then he is better. One day the breath did just go out of him. When that did happen my hope did go away."

"When my mother was sick I used to wash her and make her to be comfortable. I was sad because she was sick, but it was also a nice time because she was at home and we did spend a nice time together. I felt good to help her. I am sad she is died I miss her."

"When she was resting in bed I used to cook and feed her. My mother she did like it when I did feed to her soup. I knew she was dying of AIDS even though she didn't tell me."

Orphaning has historically been caused by relatively short-term and sporadic incidents such as trauma, war, famine or disease. Conditions regarding AIDS orphans are more chronic and arduous than those events because "... the death of a parent is preceded by a gradual physical decline and the increasing inability to perform the roles of protector, provider, guide and caregiver associated with parenting. It is this combination of having to become independent at a premature stage with living through a parents suffering, that makes the load of these children so heavy" (Loening-Voyse, 2002:105). Children are often denied their childhood when they are required to take on responsibilities in the household, caring for a parent dying of AIDS. Children are expected to perform household chores, clean wounds, deal with incontinence and see to rehydration (Foster, 2002:8). They are often shocked by what they experience in caring for their dying parent. They are exposed to circumstances which are traumatic and bewildering. Yet all experience grief when their sick parent passes away.

"I thought the pain in my chest the day my mother dies would never go away. Its better now but my heart is still sore when I do think of that day."

Literature highlights that children who care for their sick and dying parents are more predisposed to depression and anxiety and are likely to be discriminated against at school and in the community (Wild, 2001:15).

"When my mother was sick no-one did come to help me, at school no-one wanted to play with me so I did sit in the class by myself at the break-time. I did feel very sad about this and when I was caring for my mother I was anxious because I didn't know what is always right to do."

Researchers have found that children who were caring for sick parents or who had been orphaned because of AIDS experienced increased feelings of stress, grief and anxiety when discriminated against by family, school friends and members of the community (Wild, 2001:17).

3.4.1.2 SUB-THEME 1.1.1: THE AIDS ORPHANS MISSED HAVING THEIR PARENT OR LOVED ONE AT HOME TO COOK, WASH AND IRON THEIR CLOTHES

"Ikhaya" is the Xhosa word for home, a place of security, care, warmth, love, affection and belonging, but following the death of a parent or loved one, it becomes a place of challenge where children who have become orphans are ill-equipped to care for themselves. How can I feed my-self when I have no money with which to buy food? How can I cook when the relatives came and took away the cooker and the fridge? How can I wash my clothes when I have no money with which to buy soap? Home becomes barren as if the very life of a home once known has seeped away through the walls. Bewildered and alone without money the

orphans have to adapt in order to feed and clothe themselves. Quite simply they miss their mother, father or loved one who used to care for them and they need to survive.

"When I do come home from school there is no food. It was never like that before. When my mother was alive there was always food in the house. Now if I don't cook I don't eat. In Feb last year I didn't eat for 4 days. I come home from school. I do drink water and I go to lie on my bed to sleep. When I am hungry I drink more water and I sleep again. This makes me angry, because I can't learn at school when I am so hungry."

"When my father was alive he is always getting food to us. Now he is dead I must go to the neighbours and beg for food. The horrible thing is if the neighbours ask you in their home to have a meal. This is too bad because then I do feel sad because I know there are those at home that don't eat."

After the brother said this, the sister asked to see me outside the house. There she told me she used to have sex with three old men in the community to get food for the children. The siblings don't know this. She cries. It a high price to pay for food. The traditional "safety net" had unravelled, AIDS orphans are then further exposed to devastating and dangerous circumstances, which only serve to increase the scale of their personal devastation, (Matshalaga 2002a:31).

"On weekends I do the washing for my cousin and me. I cook and we clean the house together. If we are struggling. Sometimes our friends do come and help us to clean the house. When my mother was alive it was not like that. She was doing everything for us. Now we must do it ourselves."

"After the death of our mother we don't eat every day. Sometimes we don't eat for three days. When my grandmother was alive it was not like that. She did make porridge for us for school and dumplings when we do come home from school. Always she did cook for us in the evenings. I don't like being hungry. I didn't know this hunger when my grandmother was alive."

"The one thing I miss is my mother's cooking. It's difficult now to always have food to eat. Sometimes our neighbours they do cook food for us. If they don't have food we don't eat, we just go to bed hungry. The worst is to just eat cold leftovers. It was not like that when my mother was alive."

"When I am not at school I do wash my clothes, clean the house, cook and stay with my friends. I miss having my mother at home. She did always cook and clean for us even when she was sick."

"When my grandmother was alive she was taking care of us. Then it's OK. Now I must work to eat. My aunt gives me 10 Kg of mealiemeal a month. A person can't live on that. So I do go to cut wood in the bush. I sell that wood and then I do buy food to eat. We sell one stick for R 7.00. This is not enough money to buy food

with. So now I ask a friend to help me cut grass to make a broom. I do this before school so I can eat in the evenings. It was not like that before."

"I get angry when there is no food in the house. I get touchy. It was not like that before. My father when he was alive he did buy food and my sister did cook. She can't cook if there is no food."

"When my mother was alive I always had clean clothes. Now we don't always. The thing that does make me mad is if my sister is wearing my clothes. I am a boy. They are my things."

The researcher noted that none of the participants of this study was wearing new or bought clothes. Some were wearing dirty ragged clothes. One of the participants had holes in the soles of his shoes. All of the boy's trousers were short in the leg and many had buttons missing from their items of clothing. The orphans were often ashamed of their ragged clothes. The children who were washing their clothes did so in cold water. There was no money available to buy soap for washing their clothes. Some of the children wore clothes that were dirty and old. This is confirmed in the literature which indicates that seldom do the orphans have new clothes, except that which is occasionally given as a gift at Christmas time (Foster, et al, 1997:399).

"I do suffer because of my clothes. I feel humiliated. Sometimes I don't look nice because if I need a shirt I just take a shirt. I iron it and wear it even if it is not nice. Even my shoe if it has no sole, I polish it and wear it. What can I do? It's all I have so I must wear it. Sometimes I go to school without shoes. It was not like that when my mother was here because she did have a job ... before she got sick and died."

Thomas (2004:6) revealed in a study conducted in South Africa with orphans that 75% of orphan households earned less than R120 per month, and that 6 out of the 100 homes had no income at all except hand-outs from the community. Thomas found that in five of the 125 households visited on a particular day, no-one had eaten on that day or the previous day. Half of those visited had only eaten plain starch mealiemeal, sometimes with an onion or tomato or black tea, and others had eaten protein only in the form of beans or sour milk. Thomas said that one in five ate meat only on their grandmother's pension day. Thomas also found out that only one in ten children had eaten vegetables. Other empirical studies referred to by Thomas also demonstrate that orphans are at increased risk of malnutrition and stunted growth due to in sufficient food (Thomas, 2004:7). Foster goes on to say that orphans are likely to be at risk of having inadequate access to food, shelter, education and health care (Foster, 1997:85).

3.4.1.3 SUB-THEME 1.1.2: AIDS ORPHANS MISSED HAVING THEIR PARENT OR LOVED ONE TO CONFIDE IN

The impact of parental loss seems to be more severe in younger children than in adults (Cleiren, 1993:62). The care and support given to the children before they became orphans is what they knew and trusted. To confide in a parent or loved one gave peace and a feeling of being understood. The advice given was taken because the parent or loved one had their interests at heart. Now as orphans it's different. The children are not sure whom, to talk to, whom to trust and who will understand. The problem is: "no-one will love me like my father did, and I can't talk to my friends because it's not the same. They simply don't understand me or the loss I have suffered."

"When my mother was sick, I was just with her. I used to come home from school and I did talk with her. I sat in the bed with her and I talk with her. She used to ask me about school and I did tell her. I used to tell her my problems and she did listen to me. I used to sleep next to her. It made me to feel safe. I was always happy to be with her and talk to her. When she died I used to have a picture always in my mind of her in a coffin that did make me to be sad. Now I don't talk to anyone I am just sitting alone and thinking to myself."

"I was close to my uncle. I don't know my father so he is like my father to me. He brought me close to him like a son. I go to do jobs with him, eat with him. I like to tell him what is happening to my life. Now he is passed away. We did find him after he went missing. He was in a shack and had maggots all over his body. I vomited when I did see this. It was hard to get this thing out of my mind. Now it's out. I trust him and talk to him now there is no-one I trust to talk with about my problems."

"Since my mother did pass away, no-one listens to me like she did. I like to tell her about my problems now she is not here anymore. I miss her."

"I used to talk nicely to my mother at the time she was alive. I like to sit and talk to her. Now she is gone. I miss her too much."

The impact of parental loss experienced by the participants is related to the attachment they had with their parents. This loss results in a drastic change in the emotional atmosphere of the child. They experience a loss of closeness that results in insecurity. "The death of the father deprives the children of male authority while the death of mother deprives the children of crucially important mental and emotional security" (Bowlby, 1960 in Webb, 1993:138).

This loss can result in behavioural changes in the child such as withdrawal, loss of trust and isolation. They become insecure and angry because they experience the loss of a close loved one (Bowlby, 1960 <u>in</u> Webb, 1993:140).

"I was feeling I want to be alone. I didn't want to be with other children just by myself. In my mind I was always thinking' When I can get another mother?"

"I hide my feeling now. I don't want to tell my friends. I don't think they will understand and they will make fun of me."

"Sometimes I like to be alone. So I just sit behind my home away from the neighbours and I do just sit there."

"I don't talk to my friends about how I feel. I tell them to keep their nose out of my life. They know I struggle but I don't talk to them because I don't trust them. To my face they are nice but behind my back they will speak ugly things too about me. Sometimes I think it's like a test. So I try to survive. When I have a problem or I cry, I just sit in the garage alone by myself. It's better to me like that. My mother was the only one I did talk to about my problems."

All of the participants in this study said that they did not confide in their friends anymore and since the death of their parent or loved one they did not express their feelings to anyone. They all preferred just to withdraw and be alone to think and to process their thoughts and feelings. They all expressed feelings of insecurity. This is further highlighted in the literature. "Orphan children not only face the challenges of coping with the loss of their loved one but also issues associated with future bonding without the assistance of a strong parent child relationship. All of these challenges cause feelings of insecurity and mistrust and relationship difficulties with their peers and the community" (Makame, et al, 2002:459).

3.4.1.4 SUB-THEME 1.1.3: AIDS ORPHANS MISSED HAVING THEIR PARENT OR LOVED ONE TO EXPRESS CARE ON THEIR SPECIAL DAYS

Orphans in this study became very distressed when talking about birthdays, Fathers' Day, Mothers' day and Christmas. It was as if these events had represented mile-stones in their family and were now history. Family life was no longer a series of celebrations to mark special days; so special days became further indicators in the life of these children, by which to measure their loss.

"Some times I feel like I am just coming for the water. I don't celebrate my birthday any more. Mother's day is also difficulty and Christmas as well. When my mother was alive I was always having a cake and present on my birthday. On mothers day I was always getting something to give to my mother she was a good person to me and I did love her. It was nice to make a surprise to her now there is no-one to make a surprise to. Last year on my birthday my friend did come to me on my birthday and he did give me a glass of water and say happy birthday. I appreciate what he did but I just felt pain in my heart."

"On Mother's day this year at school, my friends are all talking about what they will do on Mother's day. I did move away from them when they were talking because I don't have a mother. So there is nothing I can say. It was horrible in school because the teacher did make us to all stand up and tell the class what we are doing on Mother's day. So I did just stand up and say nothing. I did cry and the teacher did tell me to sit down. I feel pain in me."

"When my father was alive he used to buy for me a cake and a present which was usually clothes. Now when it's my birthday, it's a nothing day. It's just like that. On that day I just focus on my schoolwork. If I think too much I am sore in my heart."

"This Christmas I did just go to my friend's house to eat something. I didn't have any present I was just alone in my home. I did listen to the radio then I go to him at his home and have a lovely meal. I was glad for that. It was not like that when my mother was alive. "

Three of the participants in this study didn't know when their birthdays were but all expressed feelings of pain associated with the celebrations of special days. The lack of celebrations since the death of their parent or loved one created feelings of "pain" and "hurt" and enhanced feelings associated with a lack of belonging.

Days which were previously joyous and filled with celebration were now full of sadness. The sense of loss on these special defining days woven into the fabric of family life and make defining moments in childhood, were now lost and left uncelebrated. The significance of a birthday, a birthday forgotten and the unwritten rule of birthday cakes and parties broken and discarded like a dirty rag. "Now it, my birthday becomes a day of law. I need a date of birth so I know which class to go to at school, when I can apply for my driving licence so it becomes a number void of celebration just the day on which I was born" (Adie, 2005:32-33).

The researcher would like to comment that when the orphans were describing their experiences associated with their special days, they all found it painful to recall. They remembered with fondness their special days and family celebrations and were now articulating another experience of loss. Their experiences highlight that grief is a process from which new levels of pain emerge and in which there are few rules, only experiences which defy all the rules which once governed life as it was once known (Adie, 2005:7).

3.4.1.5 SUB-THEME 1.1.4: AIDS ORPHANS MISSED A SENSE OF BELONGING

"Man's existence is an existence of relationships and involvement with the world, time, fellow-beings and God" (Kotzé, 1998:8).

When the children in this study were speaking of their experiences, it became clear that their sense of belonging and inclusion had become greatly diminished following the death of their loved one. Their whole reference for life was altered and they had become disorientated and confused. "Look into the eyes of a

typical orphan and you can see a child begging for approval and an overwhelming sense to belong" (Guest, 2001:160).

"Sometimes I am feeling like I did just come from the water."

"I was worried when my mother did die, all the time I am thinking where I can get another mother? What will I do? Who will take care of us?"

"I was thinking who will now take me to be their son because I don't even have clean clothes to wear."

"When I was at school after my mother died I was worried all the time. I couldn't do my studies because all the time I was thinking, How can I get food and money and who will take care of me?"

To belong is to be connected or to be correctly placed within (Oxford English Dictionary, 2005:46). Outside belonging is only a lack of belonging, which caused the orphans to experience fear, bewilderment and emotional pain.

"Who will take care of us now? 'Who will want me now? Who will come and take me to his family because I am dirty."

"I just have a pain deep inside me since the day my mother died."

"Why did God take my mother? Didn't he know that she was the only one to take care of me? Now what is my future who will help me and take care of me? "

"Sometimes I wish I could just die because no-one does care about me. I don't belong to anyone. I don't know my mother and my father is dead now it's like that ... so sometimes I just want to die."

"After my mother did die, my aunt came to take my brothers to her home. She said there is no room for me. The reason she did take them is because they do have a grant and I don't. I have no value to her so I can't go to be with her ... I am alone No-one did come to take me to be to them, now I have a pain in me because she did do that to me."

"The day my father died my hope died because no-one will ever love me like he did. I was close to him in his heart and now he is gone."

"After my grandmother went to be with my aunt I went to my uncle's house with my cousin. He told me he can't' help me because I am not belonging to him. It is like that so I must just survive. No-one does care about me, just God."

"When my mother was alive I was having a home. I had my room and food and it was nice. Now she is dead I stay with my aunt. I don't have a room. I just sleep in the lounge. I put chairs together and I sleep like that."

The need to belong is fundamental to the development of all aspects of our humanity. Maslow's model states that the higher needs emerge only when physical and emotional needs are met. When the emotional security needs and the love and belonging needs are unmet the individual concerned can become maladjusted and psychopathology can occur (Clark, 1999:112). (See Figure 3.4.)

"There was much fighting at my home. Neither my mother nor father was there to take care of me. My uncle was always drunk so I left home and I went to sleep in Njoli square. That time I was sleeping in a Rainbow chicken cupboard. The thing that did hurt me was no-one did come to get me. I was begging for food and I didn't wash for a week. I was cold. In the end I went with a stranger to his home and then I did go to a place of safety. It was warm there and people did care for me."

Children find themselves living on the streets because they have no-one to care for them. Their family members don't come looking for them and so they become dirty, hungry and emotionally damaged because they do not belong to anyone, they simply belong to the street (Guest, 2001:145).

Most orphans have fallen through the net of care that has traditionally come from the extended family through "ubuntu". Ubuntu has been translated as "humaneness", and is derived from the expression: umumtu ngumuntu ngabantu (a person is a person because of others/a person can only be a person through others) (Mtuze, 2004:44). "It is this system of Ubuntu which has led to such claims that there are no orphans in Africa because we are all brothers and sisters. However, the legacy of apartheid and the migrant labour system in South Africa have weakened extended family structures" (Loening-Voysey, 2001:15). In addition the AIDS pandemic has caused the number of orphan children to go beyond the coping capacity of the community (Loening-Voysey, 2001:5). This is further supported with literature that highlights that orphans are "very rarely accepted by their extended families, peers and the community at large" (Ewing, 2000:10). It would seem that one of the reasons for this other than financial insufficiency is that relatives have a fear of contracting AIDS from the orphans because the parents died of AIDS (Foster, 1999:157).

"When my father died I was just left to take care of myself. I had no money so I went to the neighbours to ask for the things I needed."

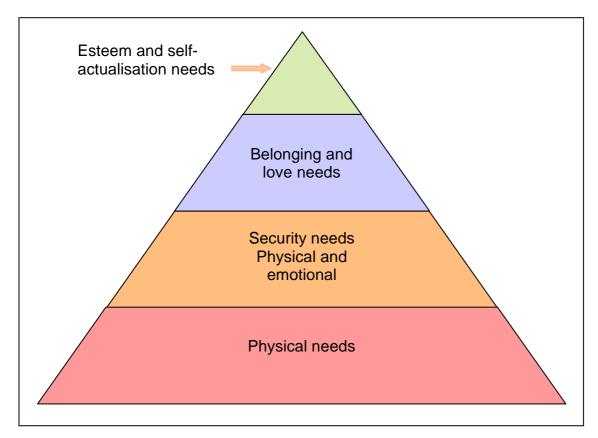
"My home is not my home anymore since my mother died. The life of my home has died and now I am staying alone and taking care of myself."

"The worst thing since my grandmother died is that I don't know where I must go to for help. And sometimes I don't know what to do"

"Once I went to my aunt for help. She told me that I am not her child so she cannot help me. It makes me to be sad that I don't belong to anyone. There is no love like your mother's and father's love because you did come from them."

"None of my family member offered to help me after my mother died. They just left after the funeral and they could see we were struggling and no-one was taking care of us. They tell us we don't belong to them but we belong to God."

"After the death of my mother I felt I was thrown away like a dirty rag, I didn't belong to anyone and no-one wanted me."



(Clark, 1999:112)

Figure 3.4 MASLOW'S MODEL OF HIERARCHY OF NEEDS

"Now that my mother has died I like to sleep in what was her room. Then I remember how I used to sleep with her when I came home from school. Then I feel like I belong, it feels nice to me."

(Van Keslem, 2000:12) indicates that "Children who have not enjoyed love have an increased chance of having a spirit of vengeance. It's subtle but as they grow up and start to notice the opportunities they have missed, they will become physically able to express their dissatisfaction. I foresee criminal activity rising in this instance." Further on in this chapter the researcher will discuss risky behaviours in which the orphans in this study were involved following the loss of their loved one.

3.4.1.6 SUB-THEME 1.1.5: AIDS ORPHANS BECAME OVERWHELMED BY A LACK OF FINANCES

"I ask myself what a person can do without money?" Following the death of their parent or loved one the orphans all experienced an increased financial burden. They were often hungry because they were without out money for food. Other household needs could also not be met because of financial insufficiency. In one of the homes of the children included in this study, there were broken windows in his bedroom and in another home a hole in the ceiling. When the children were asked about these things the reply was the same: "There is often not enough money for food so how can I buy other things that we need?" The literature highlights: "When a breadwinner of the family falls ill and dies, children who become orphans in a family incur severe loss. There is no inheritance whatsoever and they are often left destitute. Orphans frequently have insufficient food and often fall out of school to work in menial jobs to earn money to buy food, or worse they become prostitutes" (Wild, 2001:15).

"After the death of my mother I was left alone without any money. What can a person do without money? I can't buy clothes or pay school fees and I can't even buy food. This did distress me too much. Because I had no money I can't eat or wash my clothes. I feel humiliated because of this. One day I did go to school without shoes because I didn't have any. The children did laugh at me. I know my education is important so I went bare foot. Then a teacher from school did give shoes to me."

"After my mother died and my grandmother did leave to go to my aunt, I had no money. So I go to the bush to cut sticks to make brooms. These brooms are for sweeping the house. I did sell them and with that I did buy food. I didn't go to school then. If I did go to school then I have no money for food. So I do let go to my education so I can get money to eat food."

"Since my father passed away we are alone. My sister is not working. None of us are working. So I go to the neighbours and I do a piece job (casual work). I maybe get a 20 rand so my sister can get for me mealiemeal. We do then eat this. I hate it now because we eat it every day."

"When my mother was sick I was using the grant money for us to care for us all. When she did die there is no money. So I did stop going to school. I did piece jobs for the neighbours. I did wash blankets, go to the

shop to buy electricity for them and sweep their yards. They did then give me a little bit of money for me to buy for my brother and me food to eat."

In a study on attempting to combat the effects of AIDS on education in South Africa (Mwase, 2000:23), supports the statement that orphans must have access to a trouble free education. The reduction of household income following the death of a parent or carer must not be an excuse for education providers to exclude orphans from school. The report goes on to state that all relevant stakeholders in education must acknowledge the serious implications of depriving orphans of education I because of unmet basic needs.

"I felt humiliated sometimes at school because I have no money. Just this week the teacher said we must each bring R2.00 to contribute to buy cleaning products for cleaning the classroom with. I didn't have R2.00 so the children in the class did shout at me. I feel humiliated because of this. I also feel small because I can't pay school fees. When the teacher keeps asking I feel so poor because I can't pay. Last month there was a trip to a museum. I didn't go because I have no money to pay for that trip. So I did just stay to my home that day."

"Some of the children do laugh at me at school because I never have food to eat. I don't even have a few cents to buy an apple with. So I just sit in the classroom alone at the break. It's better like that. In February I had no food for four days because I decided to go back to school, so I can't work in the day. One of my neighbours did see what I was doing and gave me food in the morning and evening so I can get an education."

"The thing that does worry me the most is to become an old boy (a boy who should have had male initiation but hasn't) because I have no money to go to the bush to do initiation."

It's important to highlight that all of the male participants expressed this concern.

"The truth is that even if I can get help to my relatives. I can't tell them because I have no money for travel.

And if I get a R2.00 I will rather buy bread than to make a call to my relatives."

"One time after the death of my mother I did stop going to school and get a job. I did work in a bakery making bread from 7 in the morning till 11 at night. They pay me 20 Rand. I don't want to be a slave so I left."

"One time a shopkeeper did accuse me of stealing from his shop. I went to prison for a month. I didn't do it but they accuse me because they know I am alone and I am struggling to eat. I didn't do it and I was sad because prison was too bad to me. In that place the men do have sex with other men... I saw it and I hate

that thing it's too terrible. I never will go back there. I didn't steal but they do blame me anyway because I have no money."

AIDS orphans suffer multiple losses and because of an economically strained and socially fragmented society they are placed more at risk than other children. They lose their parents, their education and hope for the future. They are unsupported financially by the extended family and the state. The indifference which is shown to their financial need only adds to the anguish they experience following the death of their loved one. They forsake their education to meet daily needs for food and clothing. They give up their dreams to become doctors and lawyers in order to earn money for food.

"I wanted to become a doctor and care for the sick people. I gave up my education in grade 10 after the death of my mother. I realise no-one will send me to university now, besides I had no food to eat, so I must work so I can eat."

(Loening-Voysey, 2002:105) highlights the fact that "Many orphans find themselves overburdened by the constant lack of money for basic needs. They face constant rejection from the extended family that is either unable or unwilling to offer financial assistance. Therefore the absence of an adult carer illustrates that the "safety net of the extended family is not tight enough to pick up and care for orphans."

Orphans become desperate for food and clothing, driven by their need to survive. One orphan told me he worked from 7 in the morning till 11 at night assisting in a bakery. He was paid R20 a day for this work, just enough to buy him milk and bread and some mealiemeal. This opportunity of work was enough to keep him from starving and prevent him from receiving an education.

As the number of orphans increases in the AIDS pandemic and the extended family structure weakens, many orphans face living in extremely difficult circumstances because of insufficient finance available to them. This leads to "physical, social, economic and psychological morbidity and increases vulnerability to high-risk behaviour leading to exploitation, imprisonment or vulnerability to HIV infection" (Foster, 2000:2).

3.4.1.7 SUB-THEME 1.2: AIDS ORPHANS ENGAGED IN HARMFUL ACTIVITIES TO ALLEVIATE THE EFFECTS OF THE DEVASTATION THEY EXPERIENCED

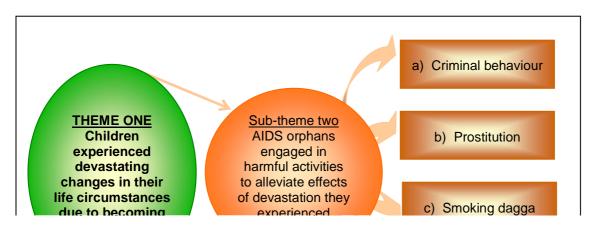




Figure 3.5 DIAGRAMMATIC REPRESENTATION OF HARMFUL ACTIVITIES AIDS ORPHANS ENGAGED IN TO ALLEVIATE THE DEVASTATION THEY EXPERIENCED

a) Criminal behaviour

It has been said that "adversity can make a person strong but it will be an unusual AIDS orphan who gains any strength from the pandemic," (Guest, 2001:18). The damage caused to AIDS orphans growing up alone will be deep and permanent. The HIV/AIDS pandemic hurts children by making them orphans and also causes their mortality to increase as well as levels of malnutrition and illiteracy. The number of children living on the streets will rise and AIDS orphans will be "forced into criminal activities, because they have nowhere else to turn for survival" (Guest, 2001:157).

"After my mother died I struggled to get food and clothes. One day I did steal washing from the washing line in a house far from mine. I stole the top because it was nice and giving me status in the community. I stole most of my clothes like this. One day I did get caught. I did community service for 6 months. I had to do cleaning in the Empilweni TB hospital it was too terrible. I don't steal anymore."

"I was a good boy when my grandmother was looking after us. When my relatives did come and take her and all our furniture I was sad. I had no clothes and food. I did bad things. I used to wait in the street and rob people. I would beat them up and steal anything I could so I can survive. I am ashamed at what I did. I don't do it now because I get help through Sisonke Sophumelela (Orphan care Programme), now I am in school, I have uniform and clothes and enough food to eat."

"Sometimes I was going to the local shop and I did steal sweets just because I wanted to. I used to think about breaking into houses to take things other people have that I don't. I decided not to do that. I just steal sweets to eat."

"I went to jail for a month for something I didn't do. I did just get the blame because people know I am doing wrong things in the community". In jail it was bad. I was beaten and all the men in my cell were doing sex with one another. I was not raped but the guy next to me he was. It was too terrible. I am never going back there again."

From these excerpts from the interviews included in this study, the orphans explained that they turned to crime to satisfy needs of survival, namely, clothing and food needs. Two of the boys interviewed were ashamed they had turned to crime to survive and expressed gladness at not behaving in a criminal way any longer.

Orphans who "slip through the net" and who end up living on the streets are at huge risk of physical and psychological damage, because of parental loss, drug and sexual abuse and being involved in criminal activity. "In 1991 they found that 80% of inmates in Sao Paulo's prison were former street children" (van Keslem, 2000:11). With a rising number of children becoming orphans in South Africa it is acknowledged that criminal behaviour will increase, because "orphans will turn to stealing to meet their survival needs and join gangs involved in criminal activities in search of their surrogate family" (Guest, 2001:159).

b) Prostitution

Orphaned girls are particularly vulnerable to sexual abuse and prostitution, because they have assumed adult responsibilities such as caring for their dying parents and raising their siblings, they are in a state of panic as they are left abandoned by their extended family and are without any means of financial support. They are bewildered by their overwhelming circumstances and will turn to prostitution to earn money to meet the basic needs of their family (Guest, 2001:160).

"I am ashamed about what I am to tell you. When my father did die I was very alone. We were six children and had no money for food. I was approached by two old men in the community to have sex with them. So I did have sex with them without using a condom. With the money they did give to me I did buy food and clothes for me and my brothers and sisters. They don't know; they just know all the time I am getting money for food."

The female orphans are particularly vulnerable to sexual abuse, primarily by older men who provide them with money for the necessities of daily living (Foster, et al, 1997:397).

"I wish I didn't do this thing because I feel dirty inside. I didn't enjoy it because they were rough and they did smell terrible. I had sex with them without a condom because then they do give me more money. I was afraid of HIV but I did have sex with them anyway. I didn't care. When I came home after I had sex with them, I was crying that my life is so low that I must do this. Then sometimes I am glad because I see my family is getting food and they are happy to have it and do love me. I love them too."

"One man in the community I was having sex with, he was about 60 years old. If I had sex with him without using a condom, he is always buying me clothes. I like the clothes that he does buy. I have sex with him for R40."

Middle-aged men seek these young girls because they are vulnerable and the men believe the young girls cleanse men infected with HIV (Guest, 2001:4). As a result of being emotionally vulnerable and financially desperate, orphan girls are temped by high-risk sexual activities such as anal sex and sex without using a condom because of the gifts given to them by these so-called "Sugar Daddies". "They succumb to these activities in order to meet basic provision needs of food and clothing for themselves and their siblings (Foster, 1998:21)." This is a high price to pay for the provision of daily necessities and gifts that would ordinarily be given on birthdays without condition.

c) Smoking dagga

"After the death of my mother I did hang out on the street with my friends. They did give to me dagga to smoke. I did like it because it makes the burning anger in me to go down and I did feel peaceful."

"After the death of my mother I did feel too sore in my heart. The only thing that does make me to forget that pain is dagga. When I smoke it, it makes the pain in my heart to be numb then I feel better again."

"Abuse, rejection, betrayal, disappointment, judgement, criticism and grief all cause pain in our lives. It has been stated that emotional pain is often more devastating than physical pain. "Medication can be taken for physical pain, but emotional pain is not easy to deal with" (Meyer, 2005:104). When pain and discomfort become more than people can withstand they turn to a substance to alleviate the pain they feel" (Meyer, 2005:105). It was for this alleviation of emotional pain that the orphans smoked dagga as it made them forget the horror of their situation and feel peaceful and carefree. One of the orphans in this study said that when he was smoking dagga.

"I am not hungry when I am smoking dagga, the pain in my heart and my tummy goes away. I do steal to get money for dagga because when I smoke it I have no pain and I like that."

"When I am smoking dagga it is like I go to another world one where there is peace and I am without pain. When I wake up I see nothing did change and so want to go to the dagga dream world again."

Pain is suffering caused by disease or distress (Oxford English Dictionary, 2005:404). "It hurts and I feel bad inside". Emotional pain felt because of devastation and suffering becomes difficult to articulate yet is very real.

"It is difficult to tell you how terrible I feel since the death of my mother. I have a pain that sticks in my chest and won't come out."

The researcher would like to make the point that the AIDS orphans in this study smoked dagga because it lessened the pain they experienced living as AIDS orphans in a township. "Children who experience psychological and emotional pain find it difficult to express that pain in socially acceptable means. They often don't talk to their peers because they are afraid they will not be understood" (De Boeck, 2005:29). Some of the orphans quite simply didn't have the words to express the depth of the pain they experienced and were unable to articulate the depth of what they felt because of fear of being rejected. Children in emotional distress will often withdraw and isolate themselves. They will try and numb the pain by smoking dagga, drinking alcohol or sniffing glue. These measures expose orphans to greater risk and often leave them to suffer the consequences of anti-social behaviour, which they can engage in when high on substances (Guest, 2001:139).

"I don't worry about stealing when I am high. I just steal because then I am brave and even if I am caught I won't feel pain. It is like that."

There needs to be much increased awareness of the distress that AIDS orphans feel in order for protective measures and safe environments to be established so they can be assisted in coping with the emotional pain they experience on becoming AIDS orphans (Reynolds in De Boeck, 2005:81-83).

d) Alcoholism

"I drink to forget. I like to be with my friends and drink and laugh and be free. I like it better than smoking dagga because when the dagga wears off you get too hungry. Alcohol is not like that. Its better when I go and I do drink with my friends it's like a family. We do trust each other and laugh. We don't drink in the tavern, because it's too risky. They are always fighting there. So we get Vodka and beer and sit outside and drink."

"I sleep well when I am drunk. I also feel no-one will push me around. I feel good when I am drunk. It's like nothing matters. I like that feeling, because in my home since my father died there are many worries. When I drink I don't worry anymore."

"I like the taste of the drink but I don't like the smell of dagga. So I drink so I don't feel pain any more. When I am drunk I don't think about how terrible my life is and how we do suffer to my home since my father died."

The excerpts from these interviews reinforce some of what the orphans highlighted about smoking dagga. They get drunk to forget the pain they experience in their lives as they do when they get high on dagga. The researcher would like to highlight the fact that only two of the male orphans in this study drank alcohol. The

others said that they did not. All of the children in this study had experienced alcoholism within members of their own families and detested the way people behaved when they were drunk. The following interview excerpts demonstrate this.

"When my mother was alive I was embarrassed. She used to go to the tavern in the day when I was at school. When I am coming home she is drunk and shouting at me in the street. I hate that I do feel humiliated. One day my cousin and I had to go with a wheelbarrow to get her. She had collapsed by the side of the road. I was angry to her because my friends in the street did laugh and I was humiliated. I hate alcohol."

"I liked to talk with my mother before she did leave us. When she is drunk it's terrible. One day my younger brother was at home. My mother was boiling water on the primus stove on the side in the kitchen. She was drunk and did knock it over and burn him. He had a skin graft and was in hospital for three weeks. That is why I do hate alcohol. She did leave us when my father died so we are alone."

"My mother drinks because my father died and she couldn't get work. She was depressed and hopeless so she drank alcohol to make her cope with all the problems we faced because of poverty, only she did make it worse."

Alcoholism and the use of dagga do not serve as responsible coping strategies because of the anti-social behaviour they produce. They do not cure the cause of the problem and are not true of proper coping mechanisms. The purpose of a proper coping mechanism is to deceive people about the actual conditions of reality in order to view it as non-threatening instead of threatening (Uys and Middleton, 1997:25-35). According to (Holden, et al, 1998:64) coping is conceptualised as a dynamic process that is the changing thoughts and acts that an individual uses to manage the external demands of a specific person or environment that is stressful. Resick (2001:118) contends that the way people interpret and cope with traumatic events will determine the eventual outcome. Furthermore, Resick (2001:118) describes four dimensions related to coping, namely, approach, avoidance, emotion, focus and problem focus.

The researcher would like to comment that the AIDS orphans in this study used avoidance as a coping strategy to numb the pain they experienced due to the devastation of their experiences of being AIDS orphans living in a township, and that they utilised smoking dagga and alcohol as a means to numb the pain they experienced due to the death of their loved one.

"My life has all become chaos since my mother died. I think I live like an animal just begging for food and living on leftovers. I wish I could cry the pain out in my chest but it gets stuck in my throat. So that is why dagga is good to me because the pain even though it is there it stops hurting for a while."

3.4.1.8 SUB-THEME 1.3: AIDS ORPHANS VERBALISED FEELINGS OF BEING

The AIDS orphans used the following words to describe how they felt: distressed, lonely, rejected, overwhelmed, abandoned, neglected, fearful, helpless, uncertain, angry, grief-stricken, suicidal, joyful, loved, glad and hopeful.

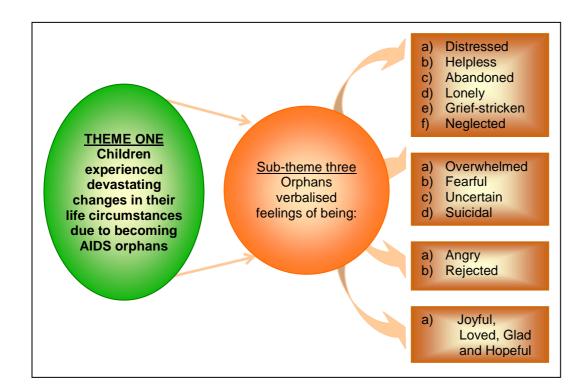


Figure 3.6 DIAGRAMMATIC REPRESENTATION OF THE FEELINGS CHILDREN VERBALIZED DUE TO BECOMING AIDS ORPHANS

The orphans included in this study all described the feelings and emotions they experienced due to the devastation of becoming AIDS orphans. They used words such as "bewildered, distressed and in pain." They were at times very articulate and willing to describe their feelings associated with their experiences; and painted in words a picture that details the feelings and emotions they experienced on becoming AIDS orphans.

"I feel like I have a pain deep in my chest. If I could take hold of it and pull it out it would be much better. But nothing does take that pain away since my mother did die. Even when I cry it is still there, sometimes it burns in my chest."

What are feelings? Are they physical sensations, emotions and awareness of both physical and emotional sensations (Oxford English Dictionary, 2005:212) or is a feeling the seemingly indefinable something which differentiates us from inanimate objects' For example, I feel joy when I pass my exams at school and I feel

pain when I experience the death of someone I love. "Feelings are physical sensations which represent my underlying nature and are expressed in the way that I behave towards myself, others and the environment which surrounds me" (Nelson, 1986:410). What is the difference between emotions and feelings? The words have been interchangeable i.e. the word "emotion" is used to describe "feelings" and the word "feeling" to describe "emotion". The word "emotion" implies movement and the word "feeling" describes a process eg I feel sad and I express anger (Nelson, 1986:41).

Several psychologists have proposed to explain where emotions come from and the behaviour that results from it. The most influential of these have been the James-Lang theory, the Cannon-Bard theory, Schachter and Singer's two-factor theory and cognitive appraisal theory (Kruger et al, 2006: 103). The James-Lang theory states that a stimulus elicits a physiological response that is interpreted as emotion. The Cannon-Bard theory has hypothesised that brain structures are involved in the experience of emotion. He proposes that those sub-cortical areas of the brain activate the physiological responses and create the conscious experience of emotion. Stanley Schachter has proposed that two factors are essential in the experience of emotion, namely the physiological arousal and cognitive interpretation or appraisal. The fourth theory is the cognitive appraisal theory which explains that the experience of emotion is not dependent upon the external situation the person experiences but rather that emotions are caused by a person's subjective appraisal of an event (Van Vunen, 2006:49). "The truth is we all have emotions; we all experience them and respond accordingly to them. Some emotions we feel cause us to experience pain and other cause us to experience delight" (Gibson, 2004:33).

"I felt such pain after the death of my mother I didn't even want to be with my friends all I want is to be alone. So in the break time at school I just sit by myself."

Before considering the accounts given by the orphans regarding their feelings and emotions, the researcher would like to like to give a brief comment about the classification of emotions and feelings. One of the most influential attempts to identify and classify emotions was made by Robert Plutchik in 1980 (Kruger, et al, 2006:103). He has proposed that human beings experience eight basic categories of emotions that motivate various kinds of adaptive behaviour: fear, surprise, sadness, disgust, anger, anticipation, joy and acceptance. He has proposed that each of these emotions help us to adjust to the demands of our environment, although in different ways (Van Vunen, 2006:50).

For the sake of clarity in the considerations of the findings of this study the researcher would like to use four basic word groups that describe feelings, namely, mad, glad, and sad and scared (Ivey, 1999:132). The following figure demonstrates how the feelings and emotions the AIDS orphans experienced in this study fit into these four word groups.

Table 3.3 REPRESENTING THE FEELINGS EXPERIENCED BY THE AIDS ORPHANS IN THE FOUR WORD GROUPS

SAD	MAD	SCARED	GLAD
a Distressed	a Angry	a Overwhelmed	a Glad
b Helpless	b Rejected	b Fearful	b Joyful
c Abandoned		c Uncertain	c Loved
d Lonely		d Suicidal	d Hopeful
e Grief stricken			
f Neglected			

The following discussion will present the findings in the four word groups beginning with those of the "sad" group.

a) Distressed

The orphans all expressed feelings of being distressed and they didn't know who would take care of them following the death of their loved one, which heightened their feeling of being distressed.

"After all the relatives left when the funeral was over, we didn't know what to do. It was just me and my brothers and sisters. I was distressed. My question was: Who will take care of us how will we survive?"

To be distressed is to suffer extreme mental pain, to experience poverty, to feel unhappy, to experience affliction, deprivation dispossession, loss of attachment to people or things, to be deprived or disinherited, to feel anguish and anxiety (Rogers, 2005:174). The following excerpts from the interviews included in this study demonstrate how the orphans verbalised feelings of being distressed.

"When my mother did pass away my family did come down from the Transkei. We were supposed to have the funeral in a week but because we didn't have money for the funeral my family did go home and leave us. I was distressed about that too much. I was very distressed because my mother she did do a lot for them and we did just have the funeral with friends that's all. I was distressed by this and I did cry."

"After my mother died, I used to just want to be alone. It was like a bad dream to me I couldn't believe what was happening and I was very distressed by this."

"The first person in my family to die was my mother, then my uncle and then my grandmother was taken away from us by our aunt. It was a bad time. When my uncle did die I went to see him. When I did see his

body it was covered in worms and this did distress me much. I was suffering by what I saw I couldn't sleep I was just seeing in my mind his body covered in worms."

"I went to my aunt to get help. She did take our grandmother to stay with her because my grandmother was having a grant. I went to ask for help because we had no food in the house. My aunt did just give us 20 rand for the month. This did distress me because how can we live on 20 rand a month?"

"I was very distressed when my father did die. I was never staying alone before now I am alone. The house is not secure and I have no food to eat. This did distress me too much and I did cry a lot at this time."

"I was very distressed after my mother did die. I got scabies and at school the children were saying horrible things to me because of this and because we are poor now my mother has died. I am too distressed by this so I just like to sit on my own in the class at the break and I do cry."

"After the death of my father, I was very distressed because no-one is working in the home. This did concern me too much and I was distressed because we had no money and no food to eat."

"I was distressed because no-one did take care of me and I had to take care of myself."

"I was distresses when I found out that my mother did die because I didn't go to visit her the day that she did pass away. That did distress me because I did love my mother too much."

The orphans described many situations that caused them to become distressed on the death of their loved one. This is confirmed in the literature that indicates "Children who become orphans feel distressed, because of the loss of their secure base and subsequent hardships which result because of the lack of emotional and physical support" (Wild, 2001:9).

b) Helpless

"I looked all around for help but there was no-one to help because everyone was also suffering. They are alone like me without help and afraid. Most days after the death of my parents I just didn't know what to do. I walked around in a daze" (Guest, 2001:32).

To be helpless, according to Rogers, is to be without assistance, without means of what is needed or what is sought by the one needing help. It is a state of being unable to manage, powerless, to be without a leg to stand upon. It is to be inadequate because of the lack of assistance and therefore being exposed to danger, to have foundations built upon the sand and therefore sink (Rogers, 2005:665). All of the AIDS orphans included in this study described feelings of being helpless because of the devastating circumstances of their

lives following the death of their loved one. The following statements the AIDS orphans made demonstrate the helplessness they experienced.

"The day my mother passed away was too terrible I did just come home and sit. I didn't know what to do. I just sat. I didn't know what to do!"

"After my father did pass away there was no-one to take care of us. We used to go to the neighbours to beg for food. If they couldn't give to us we did need we just come home and sleep with no food. We didn't know where to go to get help. It was a bad feeling to not know what to do!"

"There was no-where to go to get help we just had to do what we can do. It was like that."

"One day we did get chased away from school because we had no money to pay our school fees. We came home. We didn't know what to do so we did just pray God to help us."

"One day after my Father did pass away we had a storm and the roof did blow off our shack. We didn't know what to do. We just had to wait for our uncle to come. He did take the whole day to come to help us. We did get cold and wet."

"I was taking care of my brothers and sisters and one got sick on the weekend. I didn't know what to do because we had no money to get to the hospital. I was crying. I just carried him to the hospital. It was too terrible."

Helplessness pervaded the lives of the orphans because they needed assistance badly but no-one came. What did come was insufficient to meet their most basic of needs. They were helpless because they were ill equipped to cope with the adult responsibilities thrust upon them by orphan-hood. Foster stated "Orphans become overburdened by too many responsibilities at a young age. They feel helpless and afraid because they have been inadequately prepared to cope with these responsibilities" (Foster, 1997:85).

c) Abandoned

"I was just left by everyone. My mother died, my aunt took my brothers and I was just left to take care of myself without any money. I wanted to die because I did think I was now living in hell."

All of the orphans included in this study had been abandoned by their extended family. At their greatest time of need they were left to take care of themselves without adequate resources. The feeling of being abandoned was acute and three orphans in this study said that they wanted to die because they "felt too

bad". All of the AIDS orphans in this study said that their lives had been made very difficult because they had been abandoned. They all said that they didn't know what they had done to be treated so badly. They were like wounded solders without a place to go, left out in the cold, void of help and care, abandoned, forsaken and dismissed by their families. Literature highlights that "the number of orphaned children has gone beyond the coping capacity of the community that is why orphans are abandoned" (Loening-Voysey, 2001:15).

"I couldn't believe what had happened to me. One day I was taken care of. The next day I was left without any food. It was like that I was just abandoned. There was no-one to take care of me. I was alone."

"All I know is that when my father passed away no-one did take care of me. It was my big sister who did care for us and she didn't have a job. This made me afraid. I ask myself how we will get food."

"I ran away from home because there was too much fighting. I was alone and no-one came to get me. I knew they wouldn't because they didn't care about me. They did just leave me to take care of myself. I was 10 years old at that time."

"No-one came to us after my mother passed away. It was me and my brother and that was it. No-one did come we were just left alone."

To be abandoned is to be left alone, discarded, forsaken, to be disregarded to be cast aside without thought of (Rogers, 2005:460). It hurts very deeply to be forsaken

"I felt too much pain in my heart when no-one in my family did come to help me when they could see we were suffering when my mother did die."

"I was hurt that I was just left alone with no-one to take care of me. No-one wanted me. I was abandoned and left like a piece cloth that no-one did want."

All of the orphans in this study had experienced being abandoned by their extended family that hurt them deeply.

"I feel like a dirty person because I have been left alone. I am ashamed that no-one wants to take me in my family. They left after the funeral and they don't come to see me. I have just been left by them. I have been abandoned. What make me to be cross is that my mother was good to her family when she was alive. Now she is dead they show her disrespect because they don't care for me. They just leave me like an old shoe."

d) Lonely

The orphans expressed feelings of being lonely because of the loss of their parent or loved one, rejection of family members and because of the ridicule they faced at school and in the community by friends. They felt

ridiculed because they had become poor and because their parent or loved one had died of AIDS or AIDS related illnesses. This led to friends at school spreading false rumours about the orphans that they too were infected with HIV and would die. The orphans responded by withdrawing themselves from these relationships that caused them to become the "odd one out". They experienced feelings of loneliness as they isolated themselves by staying at home over the weekends, walking to school alone and spending the break times sitting in the class room alone.

"After my mother did die, I felt lonely because no-one did understand me like she did."

"When my uncle did die I did feel lonely because I am always with him at the weekends doing piece jobs. Now he is gone and I am alone."

"My home is lonely now my mother has died. When I come home from school there is no-one there. I am just alone. It is like that now. I feel lonely because of this."

"At school when my friends do talk about their parents I do feel lonely. I have nothing to say because my parents have died. So I just walk away and I sit by myself. I think about my mother and father but they are dead now. That makes me to be lonely."

"My grandmother was taking care of us after my mother did pass away. She is making food for us and boiling water so we can wash. She is dead now and my home is a lonely place without her care."

"My friends did know that my mother did die of AIDS. After my mother passed away we were poor and I did get scabies. My friends did say I was also having AIDS and they did go away from me. So I sit in the class at break at school and I do write poems. I am lonely because they do treat me like this."

"After the death of my mother I just stopped talking and going out with my friends because I knew that they couldn't understand what I did feel. So I just prefer to be by myself and I felt lonely because I don't talk to them anymore."

To be lonely is to be without companions, to be estranged from, to be aloof from the world, to be the odd one out, to be an out cast set apart from and to be unvisited (Rogers, 2005:893). On the death of their parent or loved one the orphans experienced extreme loneliness because they missed their parent or loved one and because their relationships with their friends changed. This is also confirmed in literature which highlights that "children who are orphaned experience profound loneliness because of the multiple losses they face following the death of their parent or loved one and because of social isolation from other children because they are now seen as different" (Wild, 2001:10).

"I felt lonely when my mother did die. I stopped going to be with my friends because my heart was too sore and I had no word to speak to them. I was always alone and I did feel lonely but too much did change. My life was different and it was better to be alone. I did miss the life I did have before when my mother was alive."

e) Grief stricken

"The day my mother did pass away was like a bad dream to me. I felt like a deep pain inside and I cried and cried."

Grief can be defined as pain, sorrow, gloom and heartache; a time of feeling wretched because of a sense of stabbing pain; a time of hell upon earth, torture, because a heart is left bleeding and wanting after suffering loss. A time of lamenting, yearning and sorrow, because of affliction with pain and loss (Rogers, 2005:828).

John Bowlby's theory on attachment would seem to underpin the basis for understanding the process of grief. Bowlby provides an explanation for the common human tendencies to develop affectionate bonds. He views attachment as a reciprocal relationship that occurs as a result of long-term interactions starting in infancy between child and care-giver. He suggests that "grief is an instinctive universal response to separation. Death is seen as the most extreme form of relationship separation and gives rise to the process of grief" (Bowlby, 1960 in Dent 2005:17).

"All I can say is that when my grandmother died it was too much to me. She was too good to me after the death of my mother and I did love her too much. She did pass away and I did feel like I did die inside my heart."

"Following the death of my mother I thought I was going mad. I kept seeing her everywhere but I knew she was dead."

"For a long time after my mother died I just cried and I cried. I didn't think it is so possible for a person to cry so much."

"All I can say is I did cry and cry. It seemed like it was not happening to me but to someone else. It was too unreal to me that my mother did pass away."

All of the orphans included in this study described prolonged bouts of crying following the death of their loved one. When being interviewed they cried in a controlled way but they all cried. Literature indicates, "Crying is an inborn attachment behaviour which, according to Freeman is primarily an appeal for the protective presence of a parent. Crying continues in adult life and is associated with loss; and the demonstration of the

loss of an attachment figure resulting in protest and despair because of the loss experienced" (Freeman, 2006:1659).

"I never knew it was possible for a person to cry so much. I didn't understand a person can make so many tears. I cried like a baby after the death of my mother I just cried and cried."

Death of a parent or loved one is a disruption in the attachment bond a person has with a significant other in his or her environment. As such a person's emotional system has to re-organise to process the loss of the attachment bond. This process generally follows four phases" (Freeman, 2006:1729). They are:

v Phase one: characterised by emotional numbing and an initial disbelief that the death has actually occurred. This lasts for a few weeks and may be interrupted by outbursts of extreme emotion

"I just couldn't believe what did happen to me I did feel nothing like I wasn't even me."

"One day I was just coming back from buying paraffin and I just started to cry I just couldn't stop. It was like that."

Phase two: includes yearning and searching. Survivors may be restless and preoccupied with the deceased, and initially prone to interpret events such as the phone ringing as coming from the deceased person. Feelings that the dead person is not really dead but alive and still with me.

"I was hanging the clothes out to dry in the garden and I did feel like my mother was standing next to me."

Phase three: the experience of disorganisation and despair. It will become apparent that attachment behaviours that were effective whilst the dead person was alive are no longer working. The grieving person begins to wonder if any part of their subsequent life is salvageable.

"I just knew that no-one would love be like my mother did and that did make me to be too sad."

"There were many times I did wish to be dead so I can be to my father."

Phase four: involves a greater or lesser degree of reorganisation. Now that the individual has come to the realisation that life has to go on various changes may begin to take place. Thoughts of the deceased may begin to take a different place in the bereaved life. Social relationships and responsibilities may also change to accommodate a world without the person who was lost. It should be understood that grief is fluid; and most individuals move among and within the stages. (Ward, 1998:3).

"I knew I had to go on in my life but I didn't know how to. Sometimes I wanted to go on and sometimes I didn't."

"I had to take care of my brothers and sisters. That is all I did do. I knew they must go to school so I did think about that only."

"I did go to a support group for orphans in our community that did help me too much because I see others are also suffering like me."

All of the orphans in this study experienced a grief response due to the loss of their loved one. Yet, what needs to be considered is that the grief process in orphans is complicated because the orphans suffer multiple losses. They not only lose their loved one, but also their financial security, their status, their schooling, their belongings, sometimes their siblings, their friends if they have to move to another home to stay with extended family and their sense of life as they knew it before. They take on responsibilities they are ill-equipped to perform such as providing for their siblings. This adds to their sense of loss as they experience also the loss of their childhood. This is highlighted in literature "Orphans experience intense feelings of grief as they adjust to their new life following the death of their loved one. They experience many losses such as loss of all household income, loss of siblings, loss of their home and their schooling as they leave their education to seek work. They are grief-stricken and hurt yet are without stability; they experience loss after loss as they just try to survive" (Wild, 2001:9). What is clear is that the orphans grieve with out support and without care. None of the children included in this study had spoken about their experiences of being orphans before being interviewed by the researcher. Maybe that's why they all cried when they spoke of their experiences.

"The prolonged deprivation of a young child of maternal care may have grave and far-reaching effects on his character and his whole life. It is proposed to be exactly similar in form to those regarding the evil after German measles before birth and deprivation of vitamin D in infancy. Death is seen as the most extreme form of relationship deprivation and gives rise to grief experiences in the one experiencing death of an attachment figure (the primary caregiver)" (Stroebe, 2002:133).

f) Neglected

"Children need love as plants need the sun in order to grow" (Meyer, 2005 65).

To neglect is to disregard, to leave uncared for to leave something undone, to let go of, to fall short of care or provision, to omit to care and provide for, or to finish to demonstrate a non-observance towards, to ignore, to shut out, to have no appreciation of, to violate, to fling to the elements, to go back from caring for, to nullify and to declare as void (Rogers, 2005:543).

All of the children included in this study were "thrown to the wind" and tossed around greatly by their devastating circumstances. Their lives were void of help. They became like saplings trying to root in harsh, dry soil. They were desperate to survive even though crushed because of being disregarded. The following statements made by the orphans demonstrate their experiences of feeling neglected.

"The worst time to me was when I was sleeping in a rainbow chicken cupboard in Njoli Square where they keep the crates for chicken. I was cold and hungry and dirty. No-one cared for me I was neglected by everyone even the people who did pass me by on the street."

"No-one did care for me after my mother died. No-one did even call to see how we were. No-one did take care of us, no-one. We did suffer too much because of this."

"We were left alone without food and help. It made me to feel like it is a test; I did treat it like that because no-one did take care of us, no one."

"The worst day of my life was when my mother did pass away. She was caring nicely for us. When she did die all the caring we knew died too. It was like that. No-one did care for us."

"I hate the people that didn't care for us after my father did pass away. They could see we were struggling and they gave us no attention and care. They did hurt me too much because of this."

Literature highlights that "Orphans need care and attention if they are to accept the loss of their loved one; otherwise they suffer depression because of further hardship they experience through being neglected" (Wild, 2001:17). The orphans included in this study were hurt and angry because of the neglect they experienced on the death of their loved one, which further damaged their self-esteem and caused them to feel unloved. One of the orphans said:

"I did feel so low that no-one did love us or want to take care for us that I just wanted to die."

The following two feelings presented are from the "mad" group of feeling words.

a) Angry

"I became so angry when I had become an orphan, I hated it. I hated being called "orphan". It was like a burning feeling in me and I all I wanted to do was to hit people. One day I was walking and I just kicked a stone all the way home. It made me to feel better."

"I punched a boy once at school he was laughing at me because I am an orphan. I punched him and made his nose to bleed. I was so angry, really angry." Anger is a very powerful emotion. It is experienced when a person is extremely displeased, irritated, frustrated or enraged by injustice of some sort; it is to experience animosity towards, resentment, or to have a bad temper towards another person or object. Anger can be described as swelling with rage or becoming exasperated by injustice and violation a sense of feeling one's blood rising and to feeling mad, very mad; and becoming incensed by an event causing the reaction of being in a huff and pushing others away (Rogers, 2005:900).

All of the children in this study had experienced anger on becoming AIDS orphans. They expressed at times that they became irrational and before the death of their parent or loved one that they had been "good children". One orphan stated

"I was never angry before. I was peaceful. Now sometimes I feel like a war in side my stomach I just want to punch something."

The following excerpts from the interviews in this study explain how the orphans experienced anger

"The day my mother did die I was very angry with God that he did take her. I still needed her and he took her. Sometimes I shake my fist to him and just shout. 'Why, God, Why?"

"I have a deep pain in me like a tree. That pain does make to be angry. Sometimes I wish I could just pull it out. I am hurt because I am now an orphan."

"I get angry when I see my friends in new school clothes and I have holes in my shoes that do make me to be angry."

"The thing that does make me to be angry is when there is no food in my home. I just burn inside and I go and I do walk around I don't want anyone to be close to me. I walk and walk till I calm down. It was not like that when my father was alive."

"I am angry that our grants took so long to come because we are still hungry and have not enough clothes."

"I am angry that no-one does take care of us. Sometimes I just want to shout because I am so angry."

The anger that the orphans experienced was because of a deep sense of injustice that they felt on losing their loved one. Their life had changed because of the loss of care and protection and they felt violated and wronged. Comments like "it was never like that when my mother was alive" and "I used to have new clothes" were made by the orphans during the interviews. The cry from their hearts was "My parents are supposed to care for me and now they are gone." The felt angered by the neglect and abandonment they had

experienced by extended family and the community members surrounding them, and were very angry when ridiculed for being an orphan. Some were aggressive in their behaviour when experiencing anger and others just withdrew into themselves. This is confirmed by McKerrow who highlights "orphans experience anger because of the unfairness of the world." "I have lost my parents and my friends still have theirs." They become with drawn or aggressive which makes, peer relationships difficult as these relationships become contaminated by their feelings of the bitterness. They feel a gross injustice because of their loss and ensued suffering (McKerrow, 1994:12).

b) Rejected

To be rejected is to be put aside, to be sent back, to be unaccepted, to be used up and cast aside, to be unwanted, to lack value, to be imperfect and to be forsaken (Oxford Dictionary, 2005:484). All of the orphans included in this study had felt rejected by their extended families, community members and friends. They had been cast aside, unwanted, considered to be a burden and of no worth. One of the orphans at the age of 14 was told he could take care of himself by a relative yet he had no money no-one to ask for help. He explains:

"I didn't even know how to make bread. How can a person live without money or bread?"

"No-one in my family wanted me after my mother died I felt rejected and that made me to be angry."

"After the death of my grandmother my extended family rejected me. No-one came to help me. They threw me away like rubbish. I was angry with them because my grandmother did help them a lot when she was alive."

"After the death of my father I went to get help from my uncle. He sent me away. He told me that he couldn't help me because I didn't belong to him. It was like that. I hate him because he rejected me and it made me to feel bad."

"I did feel so rejected by my teacher after her death of my mother. She stopped helping me after the death of my mother, because I became poor and I could not work at my schoolwork as much because I was working to get money. She didn't like me anymore. She rejected me because she thinks I am lazy. That does hurt me too much and I am sad about that."

"After the death of my father everyone rejected me: the community, my school friends and my extended family. I decided I will have to take care of me and my brother. I don't care what they think anymore. I don't need them anyway."

"My aunt took my two younger brothers to live with her after the death of my mother because they did have a grant. She didn't want me. I was rejected by her and the rest of my family because I didn't have a grant. It was like that. I know I have to forgive her for doing that but I don't like her."

"I was never an angry person but after the death of my grandmother and my uncle I was angry. The thing that did make me angry is that my family did reject me. And take all the furniture in my home. When they rejected me it was a terrible thing to me I did cry because they did hurt me too much."

"I am angry that my family rejected me and sometimes I wish them to be dead."

The orphans were emotionally deeply hurt by the rejection they experienced. Already overwhelmed with the grief of the loss of their parent or loved one, they were even caused further distress by rejection as they were pushed away at a time when they were most in need. Their psychological adjustment to their new life situation of becoming AIDS orphans was further made harder by the experience of rejection they suffered by the very people they went to for help and support. The AIDS orphans began to behave like tortoises withdrawing into their shells because they were hurt and afraid. They sought solace within themselves and relied upon themselves for protection from further hurt; yet were without the emotional reserves to cope with such hardship. Literature highlights that "Orphans who are embraced into the care of a loving family are less likely to develop deviant behaviour following the death of their loved one" (Wild, 2001:17).

One of the orphans said.

"No-one wants us any more. We are like rubbish which blows around. We go here and there but no-one wants us. We are like a dirty person who is made to be outside and we want to be loved but we are rejected. It is true no-one can love you like your mother."

The consequences of rejection in the lives of the orphans are severe. When a person is rejected certain behaviours develop within the person because they are hurt. As people we develop constructively when we are loved, cared for and accepted. When we are rejected we become hurt, broken and stunted in our emotional development (Gibson, 2004:33). The types of behaviour seen in people who are rejected fall into the following three groups according to Gibson:

- v Aggressive reactions
- v Self-rejection symptoms
- v Symptoms of the fear of rejection

Aggressive reactions include: refusing comfort from other people, rejection of others, signs of emotional hardness, scepticism, doubt and unbelief, aggressive attitudes, thoughts of revenge, swearing and foul

language, argumentativeness, stubborn defiance and rebellion and fighting. Literature indicates "72% of orphans included in a study to ascertain the effects of orphanhood were involved in physical fights and 13% of the orphans included in the study had been in trouble with the law:"(Wild, 2001:6).

"I feel so mad sometimes like I could just hit someone. I hate being rejected by my family. It makes me feel so low."

"After my mother died and no-one wanted me I decided its OK I don't need anyone anyway. I can do it myself. So the first thing I did was to ask a neighbour to show me how to bake bread. Now I can do it myself I don't need anyone."

"I didn't care about being caught doing crime after my mother died because no-one cares any way and at least in prison there is food. I hate my family and they won't come to the prison to see me any way so that is a good thing."

The orphans included in this study all used words such as hate, anger, burning anger, punishment, punching to explain the intensity of some of the emotions they experiences on being rejected. It was as if their words somehow made them to feel strong and protected.

The second group of behaviours expressed by those who are rejected are self-rejection symptoms which include low self-esteem, inferiority, insecurity, sadness, grief, self condemnation, inability to communicate, all kinds of irrational fears, anxiety, worry, depression and blocked goals which produce anger (Gibson, 2004:38).

All of the orphans included in this study said they suffered from low self esteem since the death of their loved one. They made statements like "I am low; I am poor; I am unwanted."

One of the orphans stated that he hated himself because he had become poor since the death of his father. The orphans seemed to reject themselves because they had been rejected. This self-rejection caused one of the orphans to say she would be better off dead because no-one wanted her any way.

"I can't talk to my friends about how I feel because I am afraid they will not understand me and they will laugh when I tell them how low I do feel. So I just keep it to myself. I feel sad and sometimes I just cry and cry but it doesn't make me to feel better."

"Sometimes I feel so low and I hate myself because since my father did die I am so poor. I feel so low."

"After my father did die and my stepmother did leave me I was very afraid because I did never stay alone before. I was scared about who will take care of me. No-one wanted me in my family when my father did die, no-one. That did make me to be sad."

"After my father did pass away I was so depressed I just wanted to die. No-one wanted me and I was also hungry most of the time."

"When I don't know what to do I get angry to myself because I am a stupid no body. I can't ask my father because he is dead. So I go and walk around by myself. It's like that I am so angry about this."

"To be embraced is to be loved and to be rejected is to be unloved to be unloved is to be hurt" (Gibson, 2004:1). The orphans in this study were unloved following the death of their parent or loved one and so felt hurt. The orphans demonstrated this hurt by withdrawing to avoid further hurt. They did not trust people who had previously been close to them and preferred their own company as opposed to the company of others. All the orphans included in this study stated that they would rather sit alone in the classroom at break time during school than mix with their friends.

(Gibson, 2004:1) explains that the third group of behaviours associated with rejection are symptoms of the fear of rejection, striving for achievement, performance and competition, independence and isolation "the look-after-me syndrome; I can take care of me and meet all of my own needs." The "my rights" attitude; criticism, judgement, envy, jealousy and covetousness; pride and arrogance, possessiveness and materialism emotional immaturity perfectionism and disturbed sleep patterns. Are all symptoms of the fear of rejection according to Gibson.

"After the death of my mother I tried so hard to do well at the school because it felt nice to be told I was clever."

"After my mother did die I didn't want to be with my friends any more. It was better to me just to be alone. I like to just walk and to sit alone in my room at home."

"After the death of my mother I didn't go out and play with my friends during the break at school. I just stayed by myself in the classroom. I didn't want to talk. I just wanted to do my lessons and go home."

"None of my friends know I am an orphan. I don't tell them because I don't want them to make fun of me. It's better to think about being an orphan when I am by myself and not with anyone else."

"Sometimes I am jealous because my friends who do have parents do have thing I don't have like nice clothes. Sometimes this does make me to be cross because, the only thing I have is old clothes given to me. I am jealous of children who have parents who do take care of them."

What is clear is that rejection hurts people and causes an array of cascading behaviours and emotions which demonstrate to the world that rejection causes emotional damage to those who have been rejected (Gibson, 2004:193).

The final group of feeling words to be presented in this section of this research study is from the "Scared" group

a) Overwhelmed

The orphans describe the feeling of being overwhelmed by their life circumstances on becoming orphans. They experience intense emotion because of the loss of their parent or loved one and the complicated circumstances they find themselves in because of the financial insufficiency they experience. The financial hardship experienced by orphans often leads to their experiencing multiple losses. ie loss of status, loss of schooling, loss of any more new clothes, loss of food and shelter and the loss of belonging to a family. They are bewildered, shocked and overwhelmed by the hardship they face and the intense grief emotions they feel. The world as they knew it has changed and they are overwhelmed by the enormity of their new reality.

To be overwhelmed is to be submerged by, utterly crushed, over powered by strong emotions; to experience misfortune and the debilitating effect of impossible circumstances. It's about having experienced destruction and not knowing what to do or which way to turn to get help or to get out of a situation. To become overwhelmed is to have experienced severe life circumstances or to be overcome with great delight. It is to be left floundering in circumstances not previously experienced and left not knowing how to cope (Rogers, 2005:159,749).

"I didn't think a person's life can change so much. After my mother died I was overwhelmed because every day was difficult to me. I didn't know where to get food, how to wash my clothes and how to cook. I cried too much I wanted to die."

"I went to my aunt to get help. She sent me away and I didn't know what to do. I went to the bush. I just sat there and I did cry."

"After the funeral of my mother and everyone went I was just alone. I didn't know what to do so I just sat on my bed and I did cry. I was like under a water fall of bad things that just kept falling on my head."

"I was overwhelmed when my grandmother did go to my aunt and they did take all the items in my home. I asked myself how many bad things can happen to a person. I did lose my grandmother, my home and my family."

"Everything was too much when my mother did die. I was sad all the time. My life is too difficult now because no-one is taking care to me and my brother. This makes me to be crushed in my heart."

The orphans experienced being overwhelmed because of the loss of their parent or loved one and their secure base as they knew it. Life had changed. They were without adequate provision and care. This caused the orphans to be overwhelmed by their devastating life circumstances. They became like a ship floating without an anchor and a safe place to dock. They were unable to make sense of their new reality. Literature highlights that "there in no standard response by children who have been orphaned, but that overwhelming difficulty only exacerbated the grief response and feelings of being overwhelmed by hopelessness" (Foster, et al, 1997:402).

b) Fearful

There is no fear in love. But perfect love drives out all fear, because fear has to do with punishment. The one who fears is not made perfect in love (1 John Ch 4 v 18 Holy Bible New International Version).

"I only knew fear after my mother died. Before then I was afraid but nothing like it is now. I have a burning fear of panic in me because I know I have to take care of myself and sometimes I don't know how to and we have no food. My biggest fear is not having food because with out food I will die. Once I fainted in school because I didn't have food for 3 days."

Fear is an emotion caused by impending danger, evil, alarm or dread. It causes a living being to shrink back and to become anxious of something or a situation. Fear is showing timidity or apprehension towards a person or situation and experiencing a loss of confidence towards a person or a situation. To be afraid is to be full of misgivings, mistrust or hesitation towards a person. It is to experience a nervous flutter, quivering or a shaking because of a situation or to experience despondency and despair (Rogers, 2005:860).

Following the death of their loved one, the orphans experienced extreme fear. The following excerpts from their interviews demonstrate how they experienced it.

"When I came home with my sisters from my father's funeral I was afraid. I knew that my life would change to be hard now. I was afraid because there was no-one to take care of us."

"I went to the house of my dead uncle. I went inside with my cousin's brother. I did see my uncle's body with worms on it. I was afraid and ran outside and vomited. For months after this I did have a nightmare about what I did see. I was afraid because he was a good man and this did happen to him."

"After my mother did die every night for months when I went to sleep I did have a picture of her in her coffin. I was afraid because of this."

"When my father did die I was all alone in the home. I was very afraid at night because the house is not secure. I was afraid that someone will come in and rape and kill me."

"One day after my mother did die I was at the school. I just couldn't breathe. It was like something burning in my chest it was bad. I was sweating and cold. So I did go outside my class and I did breathe. It was fear. I was terrified because my life is too hard now. But it's better now because I know I can keep going to school."

"I am afraid when we are in our shack when it rains. I do ask myself who will fix my home if it falls down. When my mother was alive her brother did come to help us. But now she is dead no-one comes. This does make me to be afraid."

"I don't sleep nice since my mother did die. I am afraid at night. I was not afraid when she was alive."

All of the orphans in this study had experienced fear following the death of their loved one. The fear was related to the lack of care that the orphans experienced after the bereavement and the images they had in their dreams and thoughts of their dead loved one. None of the orphans included in this study had had counselling of any form subsequent to the death of their loved one. Literature highlights that "following the death of their parents orphans experienced feelings of extreme anxiety and fear related to their loss and being alone" (Dent, 2005:7). Literature further indicates that: "if this fear is left untreated the orphans can become depressed, suicidal and develop post-traumatic stress disorder" (Wild, 2001:12).

"I am just afraid that's all my parent are dead I have no-one to help me. Sometimes I wish I was dead too so I can be with them."

c) Uncertain

"... He who doubts (becomes uncertain) is like a wave of the sea blown about by the wind" (James Ch1 v 6 Holy Bible New International Version).

To be uncertain is to lose the regular and to embrace the irregular. It is to become full of doubt, to become perplexed by and to vacillate between two options. To become uncertain is to become precariously placed, to flounder, and to be found bewildered to tremble, to be thrown off the scent, to be unstable insecure, to be in a quandary and to hesitate because of being unsure (Rogers, 2005:475, 485).

The orphans were all uncertain following the death of their parent or loved one because their lives as they knew it had changed beyond recognition. They were uncertain regarding the future. How will we survive? How will I continue to go to school? How will I eat? All became commonplace questions to answer. The

known was replaced by the unknown. Uncharted waters were ahead and the orphans were like boats tossed around in the sea of their harsh life circumstances. They were full of uncertainty, insecure and doubtful.

"When I thought about the future I was unsure of what would happen to me. Everything changed I was now alone and I had no money and no job and no-one to take care of me."

"Many times I didn't know what to do after my father died. I was uncertain even how to buy electricity for the meter."

"I was afraid because I was uncertain if I can continue my studies. I didn't know who will buy school uniform for me or pay my school fees."

"When I had to make decisions about my matric subjects I didn't know what to do. I had no parents to ask and no-one to go to. I did feel very, insecure."

"When I was at school I couldn't learn. I was always thinking about how I'll take care of myself. Every day I was uncertain about this."

Literature reinforces this and highlights the following. "Where there is uncertainty in the lives of orphans, there is a tendency towards elevated levels of psychological stress directly related to insecurity; caused by prolonged uncertainty" (Wild, 2001:12). Wild further highlights that "Orphans need to be placed in a secure and loving environment following the loss of their loved one. Orphans who are cared for suffer less psychological distress caused by uncertainty and fear than those who are left to fend for them selves" (Wild, 2001:18).

d) Suicidal

All the orphans in this study expressed feelings of wanting to die. Their lives had become devoid of all hope and full of pain. They suffered loss, rejection, abandonment and despair. Some of the orphans quite simply hated being orphans. They felt humiliated as if in some way it was their fault and felt low and unloved. Some said that they wanted to be free of pain and others wanted to die so that they too could be with their loved one. They were ashamed of the poverty that had come upon them on the death of their parent or loved one and hated being hungry and cold.

"The only person that did care for me was my father. After he did die no-one did care. I though I would kill myself so I can be with him."

"It's too hard for me since my mother did die. I also just want to get out of this life too."

"Many times I wanted to kill myself after my mother did pass away. One day I did go the garage to kill myself but I just sat there. I couldn't do it."

"Sometimes I feel like a walking dead person. I have no life in me, just pain. I think if I did kill myself no-one would miss me any way."

Uys and Middleton (1997:355) define suicide "as the extremity of a self inclined, self- destructive act whether it be a thought, an expression or an attempt to take ones' own life." Literature is increasingly revealing that low self esteem and negative self- attributes contribute to depression. (Harter, 1988:353) contends that "low self esteem in conjunction with depression and hopelessness seems to be the precursor of suicidal behaviour."

"After the death of my mother I just wanted to die. The pain in my heart was too bad and I didn't want to live."

"The worst thing was the sadness I did feel all the time. I was so hurt because of the rejection we did feel from the extended family. I was depressed. I did just stay in bed all day and I did want to die."

The excerpts from the interviews included in this study demonstrate that the orphans were at risk of attempting suicide. They experienced hopelessness, grief, pain, suffering and abandonment. One orphan says

"I felt I had no reason to live anymore after my parents died because no-one did love me."

a) Glad

The researcher would like to refer to the final feeling group "glad", already referred to in this section of the research study. The AIDS orphans in this study on occasion experienced "glad" emotions. The "glad" emotions the AIDS orphans experienced were linked to an intervention when help, care or support was extended to them.



Figure 3.7 A DIAGRAMMATICAL REPRESENTATION OF THE FEELING GROUPS INCLUDING "GLAD" AND INTERVENTION

The interventions the orphans referred to in order to experience feelings in the "**glad**" group were, for example, when a neighbour brought them food to eat; when they were included to play a game of soccer; when their school fees were paid by a relative or when they were given clothes to wear by a friend. This will be represented fully in the following section of this research study.

3.4.2 THEME TWO: ORPHANS REDISCOVERED HOPE TO GO ON LIVING

"The morning after my mother's funeral a neighbour came to my home and brought me food. This gave me hope because he was kind to me. "

"Weeping and mourning may last for a night but, Hope comes in the morning. A Hope that causes me to whirl round in dancing and celebration. A hope which causes me to be joyful because in my distress I was heard and I have been helped." (New King James Bible and Message Bible Psalm 130.)

The AIDS orphans in this study began to regain hope to continue living when extended family, friends, boy friends and girl friends started to reach out and help them.

"One day I was at school after the death of my mother. My friends went to the playground to eat their lunch. I went with them. We sat down and they shared their lunch with me. This gives me a hope that I can make it because they were kind to me."

Following the death of their parent or loved one hope was like a brittle thread onto which the AIDS orphans clung in order to pull themselves up. Each AIDS orphan required a different response from people in order to regain hope. Some regained hope when they were given food, others from a kind word and others by thinking about the future.

One AIDS orphan in this study felt he was suffering for a reason. He felt he had to make it in order to give others hope in his situation

"Something kept telling me to not give up so each day I did keep going. Sometimes I wanted to die but I didn't want to kill myself because then I had no future and I wanted a future."

It has been highlighted in literature "One can endure pain but one cannot survive the failure of giving up on life." (Armstrong, 2003:15.) Armstrong goes on to say "Once you have been to the brink, stood on the edge, between life and death and looked over you have seen the view from the cliff and come back down and you can share that perspective." (Armstrong 2003:17.)

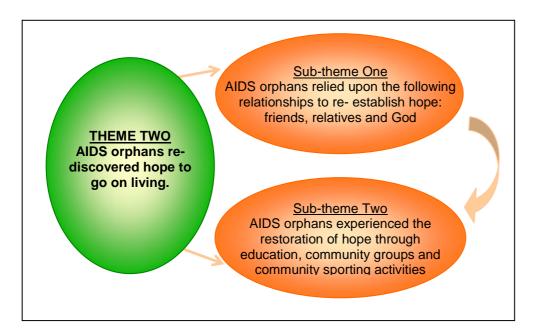


Figure 3.8 DIAGRAMMATIC REPRESENTATIONS OF HOW AIDS ORPHANS REDISCOVERED HOPE TO GO ON LIVING

The orphans clung to life. Some had contemplated suicide in the depths of their anguish and endured suffering because of the loss of their loved one. Yet they were still attending school, finding food, wearing clothes and speaking about the future. So what is hope? "It is a concept which seems to have such a vital role in our lives yet remains elusive to define even after years of inquiry" (Cutcliffe and McKenna, 2005:194).

Hope has to do with expectation and desire. It is ground upon which we stand which enables us to step into the future. It is a platform which gives rise to being secure and reassured. It's optimistic and full of promise. It's a ray of light in the darkness; it's the essence of a blue sky coming from a behind a grey cloud. It's good and lifts up the spirits of a person. Hope encourages a heart to be glad (Rogers, 2005:193). "Hope lies in the

personal experience of it and is therefore by nature difficult to define" (Cutcliffe and McKenna, 2005:189). When people in a survey were asked to choose the single best descriptor of hope from seven possible choices the three most frequent responses were: having a positive outlook, having a deep inner faith and having goals or plans (Cutcliffe and McKenna, 2005:190). Hope seems to be born out of adversity. If all is well, is there a need to have hope? All of the orphans in this study were hoping for better days. They all spoke about the future and some spoke of rediscovering love. It was as if they had passed through a torrid zone and were on the other side. It was hope that carried them through to the other side. Hope that was restored through acts of kindness and love and gave them ability to see the future.

"As we move between the dichotomies of life, we feel the pulse of life, a pull homeward. We feel the tension between giving up and going on ... Hope is the space in between ... Between the concrete and the intangible; between evidence and intuition; between religion and spirituality; between faith and doubt" (Cutcliffe and McKenna, 2005:187).

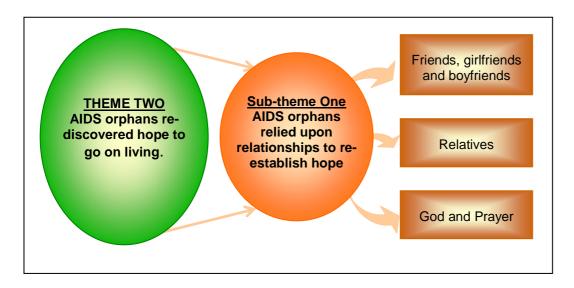


Figure 3.9 DIAGRAMMATIC REPRESENTATION OF RELATIONSHIPS AIDS ORPHANS RELIED ON TO RE-ESTABLISH HOPE

3.4.2.1 SUB-THEME 2.1: ORPHANS RELIED ON THE FOLLOWING RELATIONSHIPS TO RE-ESTABLISH HOPE

In their time of distress the AIDS orphans reached out to accept care and friendship when it was offered to them. The AIDS orphans seemed to find it easier to reach out and accept help from friends, boyfriends and girlfriends even if the relationships had not been long established.

3.4.2.1.1 Sub theme 2.1.1: Friends/boyfriends/girlfriends

All the orphans in this study relied on relationships to restore hope. Hope was fragile initially as the orphans found it difficult to accept and trust the help offered to them through their relationships with friends, boyfriends and girlfriends. The researcher would like to highlight that through these relationships, no matter how tenuous, hope was restored through demonstration of care through practical giving. Friends, boyfriends and girlfriends reached out to the orphans and gave food, shelter, clothing, kindness, a sense of belonging and love.

"I did find it difficult at first to accept help from my friend. After my mother died I have no clothes to wear. My friend told his mother and she brought for me a trouser to wear. It was hard to accept it from him but I did have a trouser with no holes and that made me glad."

The following excerpts from the orphans interviewed in this study further demonstrate how they experienced the restoration of hope through their relationships.

"My friends waited outside my house to walk to school with me after the death of my mother. I was glad because they did show kindness to me."

"After the death of my father I was alone. My teacher saw that I am suffering and she took me home to be with her every weekend. I was so glad because she was kind to me. She liked me and that give to me hope."

"Every night my friend from across the road came to get me to go to his home to eat supper with him. I was very glad about this. He made me feel cared for and that gave to me hope."

"My friend at school could see I was struggling. So he came to get me to go jogging with him every night. It was good to run. I felt free and in my mind. This gave me a good feeling that I had a future."

"On my birthday after my grandmother passed away my boyfriend gave me a birthday cake. This made me feel glad and I had hope because he remembered my birthday and give me a cake like my mother used to when she was alive."

"I do like it when my boyfriend did tell me that he does love me. This does make me to have a hope that one day I will get married and have a home and a family. That is my dream and does make me to have hope in my heart."

"I do like it when my girlfriend does hug me and hold my hand. I have a hope because she does love me and care for me."

The practical giving that the orphans experienced through these relationships enabled them in many instances to experience that the cloud of their suffering had a silver lining. They experienced care and that was the platform that enabled them to hope for a better future.

"My friend reached out to me and helped me and that gave me hope because I didn't feel alone anymore. I felt like my worries mattered to my friend and that made me know I have a future."

He went on to say

"I have a hope that I can overcome the death of my mother because when I cry my friends listen; they try and understand and help me. They encourage me that I can still be a lawyer one day."

Literature highlights that orphans left to care for themselves will be overcome with grief and sorrow as they face multiple losses not only the loss of their carer but also the loss of financial stability. They become depressed because of a mountain of hopelessness and are sad (Foster, 2002:8). Foster further says "AIDS

orphans who are living in hopelessness will be depressed and unable to support them selves materially, socially and educationally. In short they are unable to take care of themselves. In order for children who are orphaned to be helped they must be given hope through having a support structure they can rely on." (Foster, 2002:9). (Makame, et al, 2002:459) further explains: "Orphans who belong to supportive families are more able to withstand severe psychological stress and are less likely to experience hopelessness and suicidal thoughts"

"I have a hope because my friends help me. If I didn't have friends then I wouldn't have a hope. I would just give up."

Makama further indicates that "the psychological needs of an orphan relating to support and restoration of hope are as important as their physical needs if children are to over come their loss and be able to embrace their future" (Makame, et al, 2002:460). One of the orphans in this study simply said

"I did have hope because my friend reached out to me and help me."

3.4.2.1.2 Sub theme 2.1.2: Relatives

"I went to my aunts to ask for help she did give to me mealiemeal and that helped a lot."

There was a paradox that the orphans experienced in their relationships with their extended families following the death of their loved one. In one instance the extended family came to the homes of the orphans and took household items following the death of their parent or loved one and failed to give adequate support while in another instance the extended family members offered help in the form of practical support which benefited the AIDS orphans and helped them to regain hope.

Following the death of the grandmother of one of the orphan's included in this study, the grandmother's sister came to care for her and her two cousins who were also AIDS orphans

"If my grandmother's sister didn't stay to take care of us after the death of my grandmother I don't know what we would have done. We had no money and we had no food. My grandmother's sister does use her pension to take care of us. She cares for us and I have a hope for the future."

Another orphan included in this study went on to say

"My aunt was not fair to me when my mother passed away but even then when I went to her home for help she gave to me mealiemeal and that gave me hope that she felt something for me because she helped me a little bit."

The following excerpts also demonstrate how the orphans felt when offered support by their extended family. "My cousin's sister came and brought me some clothes at Christmas time. Our clothes were old by that time and I did have a hope that I can go to church again because I do have nice clothes to wear. That made me to look to the future that it will get better for me and my brother and sisters."

"The Christmas after my father died my uncle came to get me and my brothers and sisters. We went to his home for Christmas and we had nice food and also a present. It as a good time to us and we looked to the future to have a better life."

"The greatest thing that did happen to me was when my uncle did come and pay for me to go to the bush so I can become a man. This did give me much hope that I can be a man and not an old boy. I did feel after this I did have a future and this did give to me much hope."

All of the male orphans expressed the fear of: who would pay for them to go to the bush now their parents had died? They all said that to be an old boy (to have not done male initiation by a certain age) would cause them much humiliation and shame.

"I am proud to be a man in my community to be an old boy is very bad because the community doesn't respect you they mock you."

(Foster, 2002:9) highlights that the "extended family is like a net which catches family members in need. However, that net is stretched to capacity across the continent of Africa and orphans in particular have been left to care for themselves in child-headed households. It's the emergence of these child-headed households which demonstrates a breakdown in extended family capacity to care for orphans." Orphans living in CHH are more likely to be depressed because they are with out care, provision and are often suicidal because of hopelessness" (Foster, 2002:9).

In a study in Tanzania, a country also affected in the AIDS pandemic, the extended family structure has remained intact. A study that was carried out to assess the psychological well-being of orphans demonstrated that there was little difference between orphans and non-orphans living in Dar El Salaam. Orphans were demonstrated as internalising problems slightly more than non-orphans, ie such as anxiety; and there was a slight increase in the incidence of suicidal thoughts in orphans compared to non-orphans. The reason attributed for the little difference shown between orphans and non-orphans was because of the

role of the extended family. Of the 41 orphans included in the study only one orphan was living alone (Makame, et al, 2002:462).

When the extended family is in a position to be a resource to help rejected and isolated orphans by providing physical and psychological support, orphans are given hope.

"When I went to my sister who is married, her husband bought for me school books. That gave me hope because I can stay in my school and do my exams. They helped me and I was glad. No-one can make it without help."

(Foster, 2002:8) explains that "the optimum care to be given to orphans is acceptance into the extended family where care and support can be given and children can begin to recover from the loss of their parents." The researcher would like to highlight that in most instances following the death of their parent or loved one the AIDS orphans mostly experienced negative emotions. The feelings of hope that they initially experienced were short-lived and related to an intervention. However, the acts of kindness they experienced did assist in hope being restored to them although is it was fragile and short lived.

3.4.2.1.3 **Sub-theme 2.1.3: God and Prayer**

"The child reached out her hand to me. I looked into her eyes and I saw something that mystified me. In those beautiful eyes I saw a look of complete trust ... so I put on my brightest smile and took her small hand in mine. I listened as she prayed and I cried when she cried." (Klingsmith, 2005:27).

"After the death of my mother I didn't know what to do so I went to the garage and I did pray that God would help me. I just knew he was listening because I did feel calm inside my heart."

All of the orphans included in this study made a reference to God and shared experiences of praying and going to church. The orphans called to God in their distress and many were searching for the truth about God. They had questions to be answered and were all seeking comfort and hope.

"I knew after my father did die that God did become my father so I did pray to him and he did help me even to go to my Matric dinner. He did help me."

"After my grandmother died I did go to the church every Sunday and I attended bible study every week. I did know that God is with me and that did give me hope and a strength inside."

"I can say that I have a bible by my bed and I do read it every night and I do pray to Jesus. I know he does hear me because I do always sleep nice afterwards. One time I didn't read and pray and I did have a bad dream. God gives me hope and strength."

"All I can say is I know God is there and he does help me."

Some of the orphans in this study went on to say

"Whenever I did go to church it was God talking to me. The minister did speak and he did answer many questions so I did start to pray to God because I did need miracles."

"Without my prayer I would give up. I know God does listen, and a grandmother in the community does pray for me every day. This does make me to have a hope for the future."

There is paucity in literature concerning orphans and hope restored through prayer. However the literature documents incidents of their turning to God for strength and support in times of difficulty. The literature highlighted that "the external locus of control is the belief that an individual is not in control of his/her world and that things happen by chance. It is a prevalent expectancy or cognitive strategy by which people evaluate a situation". (Santrock, 1986:613). The comments the orphans made concerning prayer and God were full of warmth and intimate and meant a great deal to the other orphans who were articulating their experiences. The researcher would like to state that the orphans found comfort when praying and attending church. One orphan said:

"The minister of my church said that God is near to the broken-hearted and collects our tears. So I think when I cry God is catching my tears in his hand and that makes me to have a hope because when I cry it means something."

There is paucity in literature concerning how God and prayer enabled AIDS orphan to regain hope to continue living.

3.4.2.2 SUB-THEME 2.2: ORPHANS EXPERIENCED THE RESTORATION OF HOPE THROUGH - EDUCATION AT SCHOOL, BELONGING TO A COMMUNITY GROUP AND BEING INVOLVED IN COMMUNITY SPORTING ACTIVITIES

The AIDS orphans experienced the restoration of hope when they were involved in activities which created a feeling of belonging and caused the orphans to begin to think about the future. Hope seemed to be awakened in them when they participated in activities which they enjoyed and were good at.

3.4.2.2.1 Sub-theme 2.2.1: Education at school

"Without Education there is no future for a country, because the future of any country lies in the success of its education system preparing children for their future. Why should it be different for orphans as they are also the future generation of a country? We must help them" (Shaikh, 2001:4).

"After the death of my mother I just knew I had to go to school. Even when the rain is coming I go to school. Without Education I have no hope so I must go to school. It is like that."

"When my mother died the only time I got food was at school. School became my hope to survive. One boy in my class fainted in school because he had no food for three days. It is because of him I do get food because my friends do share to me and I can learn. Education is the key to the future so I must go to school to learn."

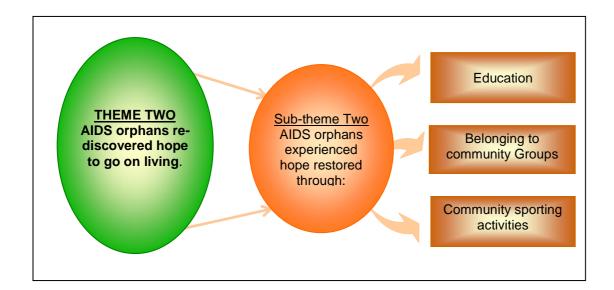


Figure 3.10 DIAGRAMMATIC REPRESENTATION OF AIDS ORPHANS EXPERIENCE OF HOPE RESTORED THROUGH EDUCATION BELONGING TO COMMUNITY GROUPS AND COMMUNITY SPORTING ACTIVITIES

All of the orphans in this study stressed the importance of their education. They enjoyed the school environment because they were not treated differently from other students and they all enjoyed not feeling different from their peers. All the orphans in this study were motivated to learn and keen to show their school work to the researcher during the interviews. They all spoke about becoming doctors, lawyers, engineers, teachers and social workers. Their dreams of a future are very much alive; and fuelled by their ability to learn and do well in school tests and to be recognised by their teachers.

When all other aspects of their environment had changed, school was the only place that remained the same, a place of learning, challenge and relative safety. Because it was familiar and relatively secure they all enjoyed focussing on their studies; it was as if their studies gave them a place to anchor for the future. The literature highlights that "Education is the hope of children who are orphans because it keeps them focussed on the future." (Reed, 2003:34). Bennell also highlights the fact that "The school environment is the friendliest of all the environments that orphans embrace, and that is why they attend school. They go to school because they aren't different there; they are simply children who need a good education to equip them for the future." (Bennell, 2005:469).

The following excerpts from the orphans' interviews demonstrate how education gave them hope:

"When I am at school I am like everyone else. I do my studies and I am always talking about the future. This is good to me because I like to learn. Education is power and when I leave school I want to be social worker so I can help people who are suffering; like me."

"Education helps me to forget my problems. When I am at school I am just learning. My best is History I love History. I have no problems when I am at school just learning. I am determined to get a good job so I must learn. That is my focus."

"My teacher is telling me I am clever because I do all my homework and I do pass the tests. This does make me to feel good inside. I have a hope for the future if I do work hard in my studies."

"Education is my hope so I go to school and learn. Even if I have a torn trouser or no food, I just drink water and I do go to school. One day I did tell my teacher about boys on my street who are not going to school. I ask him to come to talk with them. He did come and tell them about why we are to learn. He likes me too much because I am serious to my studies and that make me to have a hope in my life."

"When I go to school I do just think about my studies and that is good to me."

"I like to focus on my studies even at home. I forget about my problems when I do my studies."

Perrier conducted a study in Rwanda amongst AIDS orphans, which involved teaching AIDS orphans in a certain way. AIDS orphans were taught active Science ie constructing models of shapes and atoms out of different materials such as bamboo and conducting exciting experiments with candles and other flammable items. The researchers demonstrated that the self-esteem and attendance of the AIDS orphans going to school increased because of the attitude of the educator towards them. The AIDS orphans in this study stated that they felt cared for because the teachers were trying to understand their needs. In the environment of learning the orphans were able to learn together to experience the joy of learning and express feelings. They explored, through Science, the solving of problems and the joy of being creative, almost like a structured play. The conclusion of the research was that "Active Science alleviated the suffering

of orphans by activities which fostered the boosting of self-esteem: through creating an environment where psychological well-being was the focus of the educator toward the AIDS orphans" (Perrier, 2003:1127-1128).

The researcher would like to comment that education gave the orphans hope for the future and was important to their psychological health as it provided some normality in the devastating circumstances the orphans' faced after the death of their loved one.

3.4.2.2.2 Sub-theme 2.2.2: Belonging to Community Groups

"An individual is only as strong as the community in which he or she lives. Orphans require involvement in the community activities in order to feel a sense of belonging and stability" (Bennell, 2005:470).

The orphans involved in this study were glad to talk about the community groups to which they belonged and activities they participated in, in these groups. Belonging to community groups made the orphans forget their problems and gave then a space to belong. They all enjoyed the groups they were involved in and felt strengthened emotionally through being involved in the community activities they pursued. The following comments from the orphans' interviews included in this study demonstrate how they felt about their community groups.

"I like to go to dancing. I like it I pretend I am a princess. It is good to me because when I am dancing I forget about everything I do just pretend in my mind I am a famous dancer. Sometimes when I do dance I do feel like I can do anything in the future and that does make me to have a hope."

"I am just playing chequers (a board game) with my friends. I do play all over the weekend under a tree by my house. I do play well and the community do like lit when I do play because I have sneaky moves and it's cool."

"I go every Saturday to my special bible class. We are ten in this class. We do study and we do learn and discuss things relating to the word of God there. I love my group because we all share and I do trust them. It's good to belong there. I am strong because of that group. Last year we did go on a camp together. It was too much fun. I love my friends in this group and they do love me too. We talk about the future in this group and that does make us all to have a hope."

"One of the ladies in my community is having a community sewing project. I do go there to be with them. They are like mothers and they do teach me how to make things like mats and clothes. I do like them too much. They do give me help when I do have a problem and that does make me to have a hope. It's a good place to me I belong there and that does make me to feel good in my heart."

"In my community the most things I do is go to the playground and be with my friends. We are just there playing games on the street. We all go there after school. Mostly we just talk and play draughts on the board. I belong in that group of friends. They are always there and it's good to be to them. We do talk about the future and it does make me to a hope because I do have friends I can talk to."

The orphans in this study were encouraged in the community groups to which they belonged. They were strengthened emotionally and spiritually in these groups and were able to look to the future because of the activities they were involved in through these groups. This is highlighted in literature "We found that the orphans involved in our community activities of drawing and cooking gained a sense of belonging through these groups, escaped for a while from their problems and were boosted in their self- esteem enough to entertain thoughts concerning their futures. One orphan boy said he would like to be a chef when he grew up, he so enjoyed our community group cooking programme" (Khir, 2002:2).

3.4.2.2.3 Sub-theme 2.2.3: Community Sporting Activities

"We arrived on the basketball court, the orphans came, some without shoes some in their rags. We assembled a makeshift basketball hoop and the game began. We were all equal, all playing our hearts out all belonging to a team and desiring to be on the winning side. All that could be heard were shouts of encouragement from team members and laughter and shouts of joy. What a great sport, what great people" (D' Amato, 2006:3).

The orphans in this study loved playing games. They loved being a part of a team and they loved to win. All the orphans in this study explained that playing sport in the community gave them a sense of belonging and enabled them to be fully involved in an activity without thinking about their problems. They loved participating and also supporting a team. One of the orphans explained:

"When I play soccer it is like I am free that I can be anything. We are champions in the community. We win everything we play and that makes me to feel glad. Even if we lose I don't mind as long as it's a good game."

"I am playing hockey at my school. I like to be in a team. I feel like I do belong there. I am important to my team and they are important to me. It makes me to be glad. They encourage me and that does make me to be strong in my heart."

"When I am playing hockey I am like everyone else I don't even think about being an AIDS orphan I just am glad to have a great team to play in."

The researcher would like to highlight the gladness the AIDS orphan felt at belonging to a team.

"I play soccer for a team in the community. I love it; it makes me feel good. My friends do shout my name when I do play, and encourage me. I am a defender and I do play well so it is good to me. When I play soccer it does make me to have a hope that one day I will get a good job and be successful, just like when I do play soccer."

One thing is clear is that the orphans enjoyed belonging to a team. They loved the feeling of being encouraged and the feeling of fitting in and not being different from other children. Literature highlights that "orphans who were involved in a sports programme developed by a sports psychology department in Brisbane in Australia had better global self-worth following the project and also an increase in perceived life satisfaction. Both findings demonstrate that sporting activities for orphans help them to be more hopeful concerning their future" (Hanrahan, 2005:1). The findings of this study indicate the benefits to orphans of engaging in sports programmes in their communities. The activities helped the orphans by giving them a feeling of belonging and a place to forget their problems.

"When I am playing soccer I feel like I can be anyone. I don't feel like an orphan boy; I feel like David Beckham."

3.5 CONCLUSION

AIDS orphans face enormous challenges following the death of their parent or loved one and have to cope with many circumstances that are harsh and difficult to bear. They are flung into roles that require maturity and being responsible; yet are with out resources on every level to embrace these responsibilities. Life has become harsh, bewildering and difficult. Their well-being is compromised on every side as they seek to survive and embrace the future. Yet in the midst of all of the chaos and confusion there are rays of hope that lightened the darkness of their life as it has become and enable the AIDS orphans to speak about and look to the future.

Data of this research study was gathered by means of phenomenological unstructured interviews and personal notes written by the researcher. Data obtained from the transcribed interviews (Annexure E) and personal notes were analyses and themes and sub themes were identified to describe the experiences of AIDS orphans living in a township. An extensive literature was carried out and the themes and sub-themes were verified and placed within the context of the existing literature.

The following chapter of this research study will describe the broad guidelines that have been developed to assist Primary Heath Care Nurses, related professionals and partners in the care of AIDS orphans living in a

township. The identified themes, together with the data acquired from researcher, served as a baseline for the formulation of theses broad guidelines.

CHAPTER 4

GUIDELINES, RECOMMENDATIONS, LIMITATIONS AND CONCLUSIONS

"Pooh, Roo, Kanga, Rabbit and Eeyore all looked up. Tigger had climbed the tree and was stuck! "Hold on! "They shouted. He held on the wind blew and he held on. They looked and looked and looked. Pooh exclaimed," How can we get Tigger down?" Suddenly Christopher Robin appeared with Owl. They too looked and looked! "A plan," they shouted to Tigger, "we have a plan!" "Hold on, we are coming to get you! Hold on tight, Tigger, here we come" (Milne, 1995:21).

4.1 INTRODUCTION

The data was gathered by means of the phenomenological interviews, as described in chapter two of this study. The collected data was then organised into central themes and sub-themes and reported on in detail in chapter three of this study. This then left the researcher with the task of:

- v assessing whether the research objectives of this study had been met,
- v compiling recommendations with regard to future application of research into in the care of AIDS orphans living in a township,
- v constructing broad guidelines to enable primary health care nurses related professional and partners to extend care to AIDS orphans living in a township and,
- v identifying limitations of the study.

4.2 OBJECTIVES

This research study had a primary and a secondary objective.

The primary objective of this study was to explore and describe the lived experiences of AIDS orphans living in a township.

The secondary objective was to develop broad guidelines for Primary Health Care Nurses (PHCN's), related professionals and partners involved in the care of AIDS orphans living in a township.

In order to attain the first objective, the researcher posed to the participants the following question: *Can you tell me about your experiences of living as an AIDS orphan in the township*? The broad research question to be addressed by the undertaking of this research study was: How can primary health care nurses related professionals and partners help care for AIDS orphans living in a township? It is the conclusion of the researcher that both the objectives of this study were attained on completion of this study.

When the researcher refers to related professionals, she is referring to:

- √ Social workers.
- v Teachers and school principals.
- v Psychologists.
- v Child Protection Team Police

When the researcher is referring to partners the researcher is referring to:

- v Lay Community Health Workers.
- v Members of health forums.
- v Non-governmental Organisations (NGO).
- v Faith based Organisations (FBO's).
- v Community based Organisations (CBO's).
- v Non-profit Organisations (NPO's).

The following figure is a diagrammatic representation of the findings of Theme One and related Sub-themes of this research study.

THEME ONE
Children experienced devastating changes in their life circumstances due to becoming AIDS orphans

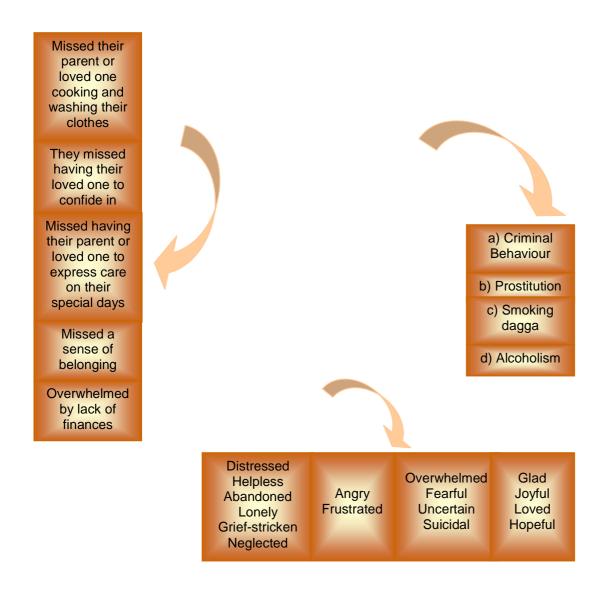
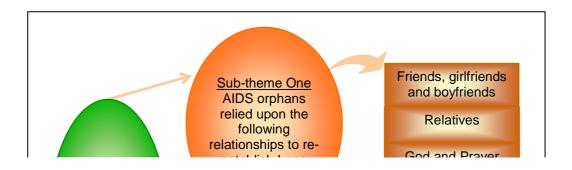


Figure 4.1: DIAGRAMMATIC REPRESENTATION OF OVERALL DEVASTATING EXPERIENCES CHILDREN WHO HAD BECOME AIDS ORPHANS ARTICULATED

The following figure is a diagrammatic representation of the findings of Theme Two and Sub-themes related to this research study.



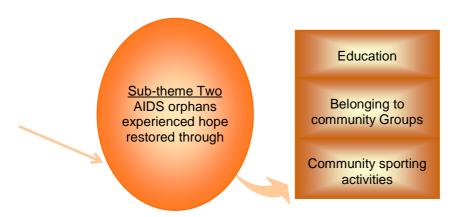


Figure 4.2: DIAGRAMMATIC REPRESENTATION OF HOW AIDS ORPHANS REDISCOVERED HOPE TO GO ON LIVING

This study emanated from the researcher's exposure to the plight of Aids orphans whilst working as a Primary Health Care Nurse in the township clinics in the Nelson Mandela Metrapole.

The stories that the orphans presented to the researcher concerning their lived experiences of living as AIDS orphans in a township were quite simply heart rending. They recounted the pain of losing their parent or loved one and described in detail the hardships they experienced as they began to live as AIDS orphan in a township. Their cry of "who will want me now I am dirty and I am poor?" is vivid in the memory of the researcher as is the look of pain in their eyes as they conveyed their story to her.

The researcher collected information rich in content describing the lived experience of AIDS orphans in a township. From this data two main themes emerged with associated sub-themes (see figure 4.1 and 4.2). The researcher then used this information as the main departure point from which to formulate the broad guidelines for PHCN's, related professionals and partners involved in the care of AIDS orphans living in a township.

4.3 BROAD GUIDELINES TO ENABLE PRIMARY HEALTH CARE NURSES, RELATED PROFESSIONALS AND PARTNERS TO EXTEND CARE TO AIDS ORPHANS LIVING IN A TOWNSHIP

By describing the lived experiences of AIDS orphans living in a township, through the research interviews, a clear picture of the world of AIDS orphans emerged. The AIDS orphans interviewed, painted a picture with their words regarding their life experiences. In this study their voices have been heard. Their world is unique, inhabited by fragile children who have suffered much hardship. They embraced the characteristics of their unique environment, which had become hostile unfriendly and harsh. They were like toddlers, learning to walk for the first time, taking new steps into a world, which for them had fundamentally changed forever.

The main focus of this study has been on the lived experiences of AIDS orphans living in a township. Accordingly, the proposed broad guidelines for Primary Health Care Nurses, related professionals and partners are to enable care to be extended to AIDS orphans living in a township. The broad guidelines have been constructed from the following sources:

- v Information gathered through the interviews included in this research study.
- v Relevant literature.
- The experiences of the researcher and field notes as well as discussions with Professionals that understood the context of this study. ie teachers, social workers and Primary Health Care Clinic Sisters.

The information shared by the participants form the basis of the guidelines. The researcher used the experiences of the AIDS orphans upon which to construct the guidelines for Primary Health Care Nurses, related professionals and partners involved in the care of AIDS orphans. The purpose of the broad guidelines is to assist Primary Health Care Nurses in their care response to AIDS orphans living in a township.

The two principal guidelines that have been formulated are:

- v to orientate the Primary health care nurses, related professionals and partners to the "life World" of AIDS orphans living in a township and,
- v to provide a broad guideline for Primary Health Care Nurses (PHCN's) and related professionals involved in the care of AIDS orphans living in a township.

The guidelines will be presented in the following manner: The principal guideline will be presented with associated sub-guidelines that will be supported by a rationale and presented with points for operational implications. This will be presented in a table format (see table 4.1).

The Guidelines will first be summarised in table 4.1 before a detailed discussion of the broad guidelines is presented.

Table 4.1 PRINCIPAL ORIENTATION GUIDELINE ONE: CREATE A KNOW-LEDGE BASE FOR PHCN'S, RELATED PROFESSIONALS AND PARTNERS RELATING TO THE "LIFE WORLD" OF AIDS ORPHANS LIVING IN A TOWNSHIP

Principal guideline	Sub-guidelines
1. Create a knowledge base for PHCN's, related professionals and partners relating to the "life world" of AIDS orphan living in a township in order to facilitate an	1.1 Create an environment conducive to holding a meeting for Primary Health Care Nurses, related professionals and partners: to present the findings of this research study and to provide an opportunity to learn via a workshop the experiences of Aids orphans living in a township.
understand-ding of the complex situation linked to caring for them.	1.2 Set up a working party from those in attendance at the above mentioned meeting to gain knowledge relating to the" life world" of AIDS orphans living in a township.
	1.3 Create an educational environment (RESOURCE POINT) within the work place of PHCN's, related professionals and partners, adding to their education relating to "the life world" of AIDS orphans living in a township.
	1.4 Provide PHCN's, related professional and partners with the opportunity to MEET AN AIDS ORPHAN included in this study who is willing to share his/her story.
	1.5 Provide PHCN's, related professionals and partners with an opportunity to, <u>VISIT NGO's WORKING WITH AIDS ORPHANS IN A TOWNSHIP</u> and listen to the NGO workers speak about their experiences of caring for AIDS orphans living in a township.
	1.6 Invite PHCN's, related professionals and partners to ATTEND A SUPPORT GROUP FOR AIDS ORPHANS facilitated and co-ordinated by an NGO caring for AIDS orphans living in a township

4.3.1 PRINCIPAL ORIENTATION GUIDELINE ONE: CREATE A KNOWLEDGE BASE FOR PHCN'S, RELATED PROFESSIONALS AND PARTNERS RELATING TO THE "LIFE WORLD" OF AIDS ORPHANS LIVING IN A TOWNSHIP IN ORDER TO FACILITATE AN UNDERSTANDING OF THE COMPLEX SITUATION LINKED TO CARING FOR THEM.

This following section of the study will present the principal guidelines, sub-guidelines rationale for each guideline and operational implications according to tables 4.1 and 4.2 of this research study.

4.3.1.1 SUB-GUIDELINE 1: CREATE AN ENVIRONMENT CONDUCIVE TO HOLDING A MEETING FOR PRIMARY HEALTH CARE NURSES, RELATED PROFESSIONALS AND PARTNERS IN ORDER TO PRESENT THE FINDINGS OF THIS RESEARCH STUDY AND TO PROVIDE AN OPPORTUNITY TO LEARN VIA A WORKSHOP THE EXPERIENCES OF AIDS ORPHANS LIVING IN A TOWNSHIP.

Rationale:

Imparting of knowledge through teaching and the sharing of experiences helps professionals to make a planned response to a problem they are facing in their professional roles.

Operational implications:

- v Organise a meeting for Primary Health Care Managers, related professionals and partners to learn through a presentation and workshop about the experiences of AIDS orphans living in a township.
- v Allocate time for PHCN's, related professionals and partners in their working day to attend the presentation in a private comfortable room free of distractions and interruptions.
- v Presentation to be given by researcher to PHCN's, related professionals and partners regarding the findings of this research study on the experiences of AIDS orphans living in a township. Included in the presentation would be the following:
 - Experiences the AIDS orphans had relating to the devastation they experienced because of the loss of their parent or loved one.
 - Activities the AIDS orphans engaged in to alleviate the suffering they experienced.
 - The feelings the AIDS orphans had relating to the devastation they experienced.
 - Accounts given by the AIDS orphans regarding how they regained hope to continue living, through activities and relationships.
- v Giving handouts to all attending the meeting relating to the findings presented to them in the presentation given and workshop.
- v Organising a workshop with the PHCN's related professionals and partners regarding their thoughts and experiences relating to the "life world" of AIDS orphans living in a township
- v Answering their questions fully to provide further insight to the "life world" of these AIDS orphans.
- v Providing an opportunity for reflection, to enable PHCN's to achieve the goal of being orientated to the "life world" of AIDS orphans living in a township.

4.3.1.2 SUB-GUIDELINE 1.2: SET UP A WORKING PARTY FROM THOSE IN ATTENDANCE AT THE ABOVE MENTIONED MEETING TO BECOME KNOWLEDGEABLE ABOUT MATTERS RELATING TO AIDS ORPHANS LIVING IN A TOWNSHIP

Rationale

The greater the knowledge base concerning the "life world" of AIDS orphans living in a township, the better the planned response by those involved in caring for them.

Operational implications

Establish from the above-mentioned meeting a party of 5 professionals who would like to be responsible to provide their professional colleagues with knowledge they acquire from the subsequent identified learning opportunities regarding the "life world" of AIDS orphans living in the township.

- v Compile a contact list with the personal details of those identified persons to be in the work party and orientate them to identify further learning opportunities to extend their knowledge base regarding the "life world" of AIDS orphans living in the township.
- v Create learning opportunities for members of the work party to gain knowledge from the subsequent identified learning opportunities to increase their own and their colleagues knowledge base regarding the "life world" of AIDS orphans living in a township.
- Arrange four monthly meetings with the working party so that they can meet and exchange knowledge and resources acquired regarding the "life world" of AIDS orphans living in a township. At that meeting the working party can compile a document relating what they have learnt regarding the "life world" of AIDS orphans living in a township, which can be typed and distributed to the professionals they represent.

4.3.1.3 Sub-guideline 1.3: Create an educational environment (resource point) within the work place of PHCN's and related professionals, that can assist with understanding the "life world" of AIDS orphans living in a township

Rationale:

Provide PHCN's with a constant learning opportunity to learn about the experiences of AIDS orphans living in a township and provide supportive information to back up what was presented and discussed in the preceding presentation and workshop. Adequate information is necessary for the Nurse to feel safe in the "life world" of an AIDS orphan.

Operational implications:

- v Establish an area within the working environment where a resource point can be created. It must be safe and easy to access by all members of staff.
- v Establish a library system whereby books, articles and DVD's can be taken home by members of staff and be returned to the resource point.
- v Collate for PHC clinics:
 - A series of research articles relating to the experiences of AIDS orphans living in a township
 - Provide a data-base for the PHCN's relating to other organisations working with AIDS orphans living in a township.
 - Make a bound copy of this research study available to PHC clinics on its completion.
 - Recommend books, articles, journals and DVD's to Primary Health Care Managers: relating to the experiences of AIDS orphans living in a township.

4.3.1.4 SUB-GUIDELINE 1.4: PROVIDE PHCN'S, RELATED PROFESSIONALS AND PARTNERS WITH THE OPPORTUNITY TO MEET AN AIDS ORPHAN INCLUDED IN THIS STUDY WHO IS WILLING TO SHARE HIS/HER STORY

Rationale:

Create a personal understanding of the experiences of an AIDS orphan living in a township. This could lead to an effectively planned strategy to enable PHCN's, related professionals and partners involved in the care of AIDS orphans, to render care to them.

Operational implications:

- v Share a personal story of becoming an AIDS orphan: One of the AIDS orphans included in this study verbalised that he/she would like to share their story personally with others, in order to help other children who have become AIDS orphans.
- v Create a safe environment where members of the selected working party could meet with the AIDS orphan in a safe loving confidential respectful manner so that the designated AIDS orphan can share his/her experiences.
- v Provide time for questions to be posed to the AIDS orphan relating to his/her experiences following the death of the loved one.
- v Provide a time of reflection regarding what has been shared by the AIDS orphan.
- Compile information gained from the session in a suitable manner so that the PHCN's nurses represented by the working party can learn from what was shared and so increase their knowledge base concerning the experiences of AIDS orphans living in a township.

4.3.1.5 SUB-GUIDELINE 1.5: PROVIDE PHCN'S, RELATED PROFESSIONALS AND PARTNERS WITH AN OPPORTUNITY TO, VISIT NGO'S WORKING WITH AIDS ORPHANS IN A TOWNSHIP AND LISTEN TO THE NGO WORKERS SPEAK ABOUT THEIR EXPERIENCES OF CARING FOR AIDS ORPHANS LIVING IN A TOWNSHIP

Rationale:

Provide PHCN's related professionals and partners with extended insight regarding the life world of AIDS orphans, to enhance further the understanding and support required when rendering care to AIDS orphans. *Operational implications:*

- v Compile a list of NGO's (Including, NPO's, CBO's and, FBO's) involved in a caring response to AIDS orphans living in a township.
- Co-ordinate a meeting between members of the working party and staff members at the abovementioned NGO's and organise a mentorship programme for PHCN's and NGO workers so that both parties can learn from the other's experiences relating to the "life world" of AIDS orphans living in a township.

- v Form a discussion group between working party members and NPO workers relating to the experiences of AIDS orphans living in a township.
- v Organise visiting opportunities for PHCN's, related professionals and partners to visit AIDS orphans in their homes accompanied by NGO workers, in order to gain insight into the real needs of AIDS orphans living in a township.
- v Feed back to the PHCN's they represent.

4.3.1.6 SUB-GUIDELINE 1.6: INVITE PHCN'S, RELATED PROFESSIONALS AND PARTNERS TO ATTEND A SUPPORT GROUP FOR AIDS ORPHANS FACILITATED AND CO-ORDINATED BY AN NGO CARING FOR AIDS ORPHANS LIVING IN A TOWNSHIP

Rationale:

Further extend assistance to PHCN's related professionals and partners to enable them to acquire knowledge regarding the "life world" of AIDS orphans living in a township.

Operational implications:

- v Identify orphan support groups that are running in the townships for AIDS orphans, primarily through the NGO structures.
- v Attend a support group for AIDS orphans facilitated by an NGO already in operation in the township community.
- v Listen and learn from the AIDS orphans regarding what is being shared in their support group.
- Report to other members of the working party the insights gained regarding the "life world" of the AIDS orphans, from attending the support group as an observer.

Table 4.2 PRINCIPAL GUIDE-LINE TWO: PROVIDE A BROAD GUIDELINE FOR PHCN's, RELATED PROFESSIONALS AND PARTNERS INVOLVED IN EXTENDING CARE TO AIDS ORPHANS LIVING IN A TOWNSHIP

ı	Principal Guideline	Sub-guidelines
4.2	To provide a broad guideline for PHCN's, related professionals and partners involved in extending care to AIDS orphans living in a township, in order to facilitate a	 4.2 STRATEGY: To provide a planned care response to address the needs of AIDS orphans living in a township. 4.2.1 TIME: PHCN's and their managers to identify staff hours required to actualise a care response for AIDS orphans living in a township. 4.2.2 FINANCE: PHCN's and Managers to formulate a business plan to municipal and government departments to motivate for finances, to allocate staff hours necessary to provide a care response for AIDS orphans living in a township. 4.2.3 STAFF: For PHCN managers, to review the allocation of staff hours to assist PHCN's involved in the care of AIDS orphans.
	planned care	4.2.3.1 Identify PHCN's and clinic volunteers interested in caring for AIDS orphans living in a township and develop a system for

Principal Guideline	Sub-guidelines
response to	collecting data to identify actual and
address their	potential AIDS orphans. 4.2.3.2 Provide de-briefing sessions for PHCN's
needs.	and volunteers caring for AIDS orphans.
	4.2.3.3 PHCN's to co-ordinate volunteers assisting them in the care of AIDS orphans
	4.2.3.4 PHCN's to receive professional development training for the co-ordination
	and facilitation of running a support group.
	4.2.4 SERVICES : PHCN's and volunteers to provide
	AIDS orphan support groups for potential and actual AIDS orphans
	4.2.4.1 Initiate a "Planned care response"
	programme for AIDS orphans living in a township.
	4.2.4.2 PHCN's to organise and facilitate working party meeting regarding referrals with
	related professionals caring for AIDS orphans in a township
	4.2.4.3 PHCN's to co-ordinate and facilitate
	workshops for orphans regarding how and where to access help and support

4.3.2 PRINCIPAL GUIDELINE 2: TO PROVIDE A BROAD GUIDELINE FOR PHCN'S, RELATED PROFESSIONALS AND PARTNERS INVOLVED IN EXTENDING CARE TO AIDS ORPHANS LIVING IN A TOWNSHIP IN ORDER TO FACILITATE A PLANNED CARE RESPONSE TO ADDRESS THEIR NEEDS

4.3.2.1 SUB-GUIDELINE 4.2 <u>STRATEGY</u>: TO PROVIDE A PLANNED CARE RESPONSE TO ADDRESS THE NEEDS OF AIDS ORPHANS LIVING IN A TOWNSHIP

Components of the strategy are time, finance, staff and services. These will be represented in the following sub-guidelines.

4.3.2.1.1 Sub-guideline 4.2.1 <u>Time</u>: Primary health care nurses and their managers to identify staff hours required to actualise a care response for AIDS orphans living in a township

Rationale:

Through identification of staff hours required, a structured plan can be created to actualise the role PHCN's and clinic volunteers can have in initiating a care response to AIDS orphans living in a township.

Operational implications:

- v Organise a meeting between PHCN's and their managers to determine how many staff hours will be required of the PHCN's to:
 - identify and organise clinic volunteers to collect data from actual and potential AIDS orphans identified through the existing clinic services,
 - co-ordinate and evaluate that data,
 - facilitate debriefing sessions for the staff,
 - co-ordinate and facilitate staff development and evaluation of orphan support groups,
 - organise and implement a support group programme and buddy system for the AIDS orphans,
 - organise, co-ordinate and facilitate a working party for referrals for the AIDS orphans,
 - organise and facilitate a Planned Care Response Programme and give
 - feedback to PHCN managers.
- v Plan number of staff hours required to administrate the above-mentioned actions.
- v Plan number of staff hours required with managers in the co-ordination of the above-mentioned activities.
- v Assess number of staff hours required in the evaluation of the above-mentioned, including feedback to managers.

4.3.2.1.2 Sub-guideline 4.2.2 <u>Finance</u>: PHCN's and Managers to formulate a business plan to municipal and government departments to motivate for finances, to allocate staff hours necessary, to provide a care response for AIDS orphans living in a township

Rationale:

Financial assistance will be required to adjust staff hours. Through professional motivation a request is more likely to be favourably granted than rejected.

Operational implications:

- v Read and review existing business plans and motivations that have already been previously successful when submitted for approval.
- v Learn how to write a business plan by attending workshops and through accessing written resources.
- v Motivate in the business plan:
 - Aims
 - Strategy

- Cost
- Expected outcomes: for all of the above-mentioned recommendations
- Effectiveness measurements
- Reasons for adjustment required in staff hours
- v Present a business plan to independent persons for evaluation before submission to municipal and government structures.
- v Prepare an accompanying presentation with the business plan highlighting the results of this research study and recommendations made.
- Utilise the business plan to give insight to personnel in the municipal and government structure regarding how, through the adjustment of staff hour PHCN's can be utilised to initiate, implement and evaluate a care response to AIDS orphans living in a township.

4.3.2.1.3 Sub-guideline 4.2.3 <u>Staff</u>: For PHCN managers, to review the allocation of staff hours to assist PHCN's involved in the care of AIDS orphans

Rationale:

An improved understanding by PHCN managers regarding the role PHCN's could have in caring for AIDS orphans, could lead to adjusted staff allocation to enable PHCN's to be really be effective in their ability to care for AIDS orphans living in a township.

Operational implications:

- Organise a meeting for PHC Managers and PHCN's regarding the possibility of PHCN's responsible for ARV roll-out, to begin to identify through this service children who will become orphans due to their parents having AIDS.
- Identify PHCN's hours required through this service of ARV roll out, to begin to assess and plan care for the potential AIDS orphans of these clients.
- v Compile a list of children identified as becoming potential AIDS orphans. Draw up a contact sheet for each potential orphan with identified needs.
- v Compile a list of existing orphans accessing other clinic services ie TB and family planning services and also draw up for them a contact sheet of their details and their needs.
- v Plan a strategy with the parents who are attending the clinic for ARV/TB treatment regarding the care of their children who will become orphans ie "Planned Care Response".

4.3.2.1.3.1 Sub-guideline 4.2.3.1: Identify PHCN's and clinic volunteers interested in caring for AIDS orphans living in a township and develop a system for collecting data to identify actual and potential AIDS orphans

Rationale:

A properly focused response to caring for AIDS orphans based upon recent data concerning AIDS orphans will optimise the care response of PHCN's to AIDS orphans living in a township.

Operational implications:

- v Identify PHCN's and volunteers interested in the concept of assisting the PHCN to assess the needs of actual and potential AIDS orphans living in a township.
- v Determine the goal of the data collection "to identify where AIDS orphans are and the needs they have."
- Organise volunteers in collection of necessary data regarding AIDS orphans
 - Collate information received from ARV roll-out clients.
 - Compile a comprehensive needs assessment regarding potential orphans in a structured and comprehensive manner.
 - Co-ordinate meeting with other working party members.
 - Formulate a system of referral amongst related professionals.
 - Liaise with other clinics and working party groups involved in a care response to AIDS orphans living in a township.

4.3.2.1.3.2 Sub-guideline 4.2.3.2: Provide de-briefing sessions for PHCN's and volunteers involved in caring for AIDS orphans

Rationale:

Regular de briefing prevents build-up of negative emotions that can lead to burn out (Payne & Firth-Cozens, 1987:278-280).

Operational Implications:

- v Co-ordinate monthly debriefing meeting for all members of the working party.
- v Arrange the above-mentioned meeting during working hours.
- v Motivate for the meeting to be co-ordinated by a psychologist or counsellor.
- v Encourage all members of the working party to attend.
- v Limit time of meeting to one hour, which will be co-ordinated in a confidential, sensitive and respectful manner.

4.3.2.1.3.3 Sub-guideline 4.2.3.3: PHCN's to co-ordinate volunteers assisting them in the care of AIDS orphans

Rationale:

The Primary Health Care Nurse is in the unique role of having access to a multidisciplinary team and being a point of contact for AIDS orphans to access help and support. The more volunteers the PHCN's has to assist her greater the care response can be to AIDS orphans living in a township.

Operational implications:

- v Allocate a team of volunteers to assist the PHCN's who are caring for AIDS orphans.
- v Collect data utilising the volunteers, regarding AIDS orphans and potential AIDS orphans, and coordinate referrals with the PHCN to the working party.
- v Arrange feedback meetings between PHCN's and volunteers.
- v Access AIDS orphans through the following structures:
 - AIDS patients attending ARV treatment programmes,
 - AIDS patients attending TB treatment programmes,
 - AIDS orphans accessing treatment themselves for services of the clinic ie Family Planning and treatment of minor illnesses.
- v Responsibility of the PHCN's to include the following:
 - Co-ordinate the schedule of the volunteers,
 - Co-ordinate the assessment documentation of the volunteers,
 - Inform volunteers regarding weekly meetings, working party meetings, and debriefing meetings,
 - Accompany volunteers to the work party meetings where referral can be made to related professionals and partners.

4.3.2.1.3.4 Sub-guideline 4.2.3.4 PHCN's to receive professional development training regarding co-ordination and facilitation of running a support group

Rationale:

Assistance given to PHCN's about the acquiring of knowledge on how to convene, facilitate and evaluate workshops will make them effective in their role and prevent frustration, through having not been taught the skills necessary to perform a task.

Operational implications:

- v Provide an opportunity for PHCN's to attend a staff training session regarding how to co-ordinate, facilitate and evaluate a support group.
- v Provide follow-up support in terms of training and evaluation of PHCN's co-ordinating, facilitating and evaluating support groups.
- v Provide an assessment tool to assess the competency of PHCN's in the running of support groups.
- v Attend 3 support groups co-ordinated and facilitated by NGO's, prior to facilitating and coordinating own orphan support group.
- v Evaluate the role of the PHCN's every four months utilising peers and managers to assess the effectiveness of the PHCN's involved in coordinating and facilitating orphan support groups.
- v PHCN's coordinating and facilitating orphan support groups to keep professional records pertaining to the orphans support group.

4.3.2.1.4 Sub-guideline 4.2.4 <u>Services</u>: PHCN's and volunteers to provide AIDS orphan support groups for potential and actual AIDS orphans

Rationale:

Utilise clinic and existing staff structures to provide a support service to AIDS orphans to elicit care, counselling and support to them, this will provide better support to the AIDS orphans who are living in a township.

Operational implications:

- v Visit existing orphan support groups and gain insight as to how to co-ordinate and facilitate orphan support groups.
- v Access resource material that will be used to co-ordinate and facilitate an orphan support group.
- Disseminate information to the orphans regarding the date, time and venue for the support group.
- Present to the designated AIDS orphans who attend the support group, a plan regarding how the support group will be co-ordinated and the topics that will be covered. ie grief, rejection, low self-esteem etc. The PHCN's should also give the orphans a timetable of subsequent scheduled support group meetings.
- v Co-ordinate a buddy system pairing each orphan with another and suggests to them that they meet together every week for a time of encouragement and support. Ideally orphans should be paired with someone who lives close to their home and is of a similar age.

4.3.2.1.4.1 Sub-guideline 4.2.4.1: Initiate a "Planned care response" programme for AIDS orphans living in the township

Rationale:

Through adequate planning problems can be identified and alleviated. If parents dying of AIDS plan care for their children who are to become orphans AIDS orphans are less likely to be left void of care and support when their parents die and less likely to become destitute.

Operational implications:

- v Help clients attending the clinic for Anti-Retroviral ARV treatment, to make a planned response regarding the care of their children who will become orphans on their death.
- v Provide an opportunity for the parent dying of AIDS to plan for the care of their child who will become an orphan.
- v Discuss with the parent dying of AIDS:
 - What plans are in place for their funeral? Give advice or refer them to a professional so that adequate plans can be put in place.
 - Who will take care of the child after they die?
 - How the child will be provided for financially following their death?
 - What they have told their child about their death?
 - How have they prepared the child for their death?
 - What legal documents have been secured so that the parent's house, if applicable, will be left to the child?
 - Does the child have all the documentation they require such as a birth certificate or Road to Heath Card and does the child know that the death certificate must be kept in a safe place? Does the child know how to get a death certificate?
 - Is the child prepared for the procedure of the funeral and who will take responsibility for that?
 - Does the child know how and where to access help once the parent has died.
 - Does the child know who will take care of him/her immediately following the funeral? Has he/she met that person? Does he/she have a relationship with that person?
 - Does the child have a social worker to help him/her and foster care parent apply for the correct grant?
 - Is the school aware of the home situation, so that concessions can be made regarding school fees etc?
 - Are church and community leaders aware of the situation so that help can be given to the child?
 - Have the relevant NGO's been contacted to provide help and support?
 - Contact PHCN's to provide time for parents dying of AIDS to make plans for their children and to refer dying parents to appropriate services for help and support.

4.3.2.1.4.2 Sub-guideline 4.2.4.2 PHCN's to organise and facilitate a working party meeting regarding referrals with related professionals caring for AIDS orphan in a township

Rationale:

A co-ordinated meeting with all parties involved in the care of AIDS orphans will make the care response needed in meeting the needs of the AIDS orphan living in a township adequately planned and thus properly effective.

Operational implications:

- Identify key stakeholders involved in a care response to AIDS orphans ie social workers, teachers, school principals, psychologists, clinic volunteers, church leaders, community leaders, Child Protection Team Police, NGO's FBO's and CBO's.
- v Convene and co-ordinate the meeting of all identified stakeholders and convene subsequent meetings of this working party.
- Document ways that PHCN's, related professionals and partners are able to initiate a care response to AIDS orphan's for example, schools could start orphan support groups, NGO's, in some instances, could provide food and clothing, and social workers could look for suitable foster facilities and help access appropriate grants.
- Formulate a resource group so that referrals can be made by all the stakeholders to access help, care and support for the orphans that they represent. Through this mechanism a comprehensive referral system can be created whereby AIDS orphans living in a township can be helped and supported and professionals involved in caring for AIDS orphan will know from where they are able to access help and support.
- v Arrange feedback sessions for PHCN managers regarding the success of this work party related directly to the orphans who have been assisted by this group.

4.3.2.1.4.3 Sub-guideline 4.2.4.3: PHCN's to co-ordinate and facilitate workshops for AIDS orphans regarding how and where to access help and support

Rationale:

AIDS orphans who are advised where and how to access support are less likely to become destitute.

Operational implications:

- v Convene a workshop meeting with identified AIDS orphans.
- v Utilise the meeting as a forum for giving information to the AIDS orphans regarding where and how to access help and support.
- v Give advice on:
 - when to come to the clinic to access medical help,

- what to do if the clinic is closed,
- how to access a social worker,
- how to resolve problems before they occur eg to see school principal and explain why school fees not paid before being chased from school,
- how to access food parcel,
- who to speak to if having a problem and need advice,
- where to go to access counselling facilities,
- how to approach NGO's for help and support, and
- inform the AIDS orphans of services the clinic provides for them ie support group meetings;
 system of referral; a buddy system and treatment services.

4.4 LIMITATIONS OF THE STUDY

It is recognised by the researcher that, as with all qualitative studies, the sample size and the specific nature of the sample and research context prohibit generalizations being made. However, the richness of the data collected provided much insight into the lived experience of AIDS orphans living in a township and the assumed benefits of utilising a phenomenological approach were therefore realised.

Specific limitations that were acknowledged are:

- Interviews were conducted in three townships only. This study does not include AIDS orphans living in foster care or residential care. The researcher would also like to indicate that of the eight interviews carried out two of the orphans did not state that their parent or loved one died of AIDS. They experienced that their parent or loved one had the symptoms of AIDS and died of TB. To ascertain the cause of death of the parent or loved one was sometime difficult because of lack of disclosure to the children by their parents or loved one of their HIV status and the shame the children felt disclosing that their parents had indeed died of AIDS.
- Although confidentiality was ensured anonymity was challenged because some of the AIDSorphans included in this study stated that they had a reaction from community members when the researcher arrived at the orphan's houses to interview them. They said they felt different and didn't like that. However, they also stated that they did like to talk about their experiences and felt special because someone took an interest in their story. The researcher was careful not to disclose the reason for the home visit, but the house had been identified by the community who knew the child living there was an AIDS orphan.

4.5 RECOMMENDATIONS FOR FURTHER RESEARCH

In the light of the research findings and indicated limitations the following recommend-dations for nursing practice, education and research were formulated.

4.5.1 RECOMMENDATIONS FOR NURSING PRACTICE

- v Guidelines need to be made available to all PHC clinic managers in the Municipality.
- v Municipal and local government personnel need to be made aware of the findings of this study and guidelines.
- v Guidelines need to be refined to develop an individual programme for PHCN's in their clinic settings in the township.

4.5.2 RECOMMENDATIONS FOR NURSING EDUCATION

- v Students should be given a course component regarding the extensive role of the PHCN in South Africa context.
- The nature and extent of PHCN component of the basic nursing course in different institutions needs to be evaluated and supplemented where necessary to include the role of PHCN's in initiating a care response to AIDS orphans living in a township. The subjects of AIDS and AIDS orphans cannot be separated because of the health and psycho-social response required by nurses, particularly PHCN's related professionals and partners to initiate a care response in the midst of a social catastrophe.
- v In-services, courses and workshops need to be developed to enhance the skills of PHCN's in working with AIDS orphans.
- In-service training to validate and extend the role of the PHCN in the uniqueness of their role should be introduced. To equip them to be the key stakeholders, in facilitating and co-ordinating a planned approach in response to AIDS orphan living in a township.
- v In service training should be instituted to develop leadership, communication, administration coordination, and facilitation and evaluation skills.

4.5.3 RECOMMENDATIONS FOR NURSING RESEARCH

The formulation of a questionnaire based upon the themes identified in the interviews of this study could be developed for use in a quantative study, thereby testing the generality of the research findings of this study.

- v As comparisons qualitative research studies could be developed to research the lived experience of non-AIDS orphans living in another township or AIDS orphans living in foster care or residential care or even AIDS orphans living as street children.
- v A new model for co-ordinating a care response could be developed through the extended role of the PHCN.
- v A quantitative study could be done to evaluate the effectiveness of a planned care response programme co-ordinated by PHCN's in meeting the needs of AIDS orphan living in a township.
- v A model to initiate a care response to AIDS orphans co-ordinated through the unique role of the PHCN's could be developed.

4.6 CONCLUSION

"Speak up for those who cannot speak up for themselves, for the rights of all those who are destitute". (Holy Bible New International Version Proverbs CH 31 v 8.)

This study provides insight into the lived experience of AIDS orphans living in a township, and presents findings that can be used as a foundation upon which a care response can be initiated to provide care for them. Understanding the "life world" of AIDS orphans living in a township is vital before planning a care response to meet their unique needs. To tell their story has been as privilege.

The role of the PHCN is unique and is in essence the fulcrum upon which a care response to AIDS orphans can be balanced. The PHCN has a pivotal role in the care response to AIDS orphans, because of the contact PHCN's have with AIDS orphans and contact with the related professionals and partners involved in the care of AIDS orphans. If supported their role could be vital to initiating a care response to AIDS orphans living in a township. The role of the PHCN has to be re-contextualised in the reality of an increased population of AIDS orphans living in the township. Just as it had to be re-contextualised to initiate care to those infected with HIV and dying of AIDS. Support, equipping, resources and validation of their unique role is what is necessary if they are to be the fulcrum upon which a care response to AIDS orphans living in a township is to be balanced and co-ordinated.

The researcher would like to conclude this study with the following:

"When my mother died I knew it was AIDS but she didn't tell me. She left me and no-one was there to take care of me. I sat alone and I did cry. I was hungry and cold and dead inside. I didn't want to live. I was alone; I cried and the tears did burn down my face. Who cares about me? I am an

orphan now. Will I die? Will anyone come? Does anyone care? "Who will want me now I am a dirty orphan? I belong to no one."

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ANNEXURE A

LETTER FROM ADC



FACULTY OF HEALTH SCIENCES FAKULTEIT GESONDHEIDSWETENSKAPPE IFAKHALTHI YEZEMPILO

Mrs SL Frood 46a Kragga Kamma Road Sunridge Park PORT ELIZABETH 6045

Enquiries: Mrs G Ehbel

17 September 2004

Dear Mrs Frood

FINAL RESEARCH PROPOSAL: 2004

Please be advised that your final research proposal was approved subject to the following amendments/suggestions/recommendations being made to the satisfaction of your Supervisor:

(i) That it was suggested that "Kwazakhele" be reflected in the title as it is specifically used in the

research questions and objectives:

- (ii) that it was suggested that the title be amended as follows:

 CO-CONSTRUCTING GUIDELINES FOR CARE AND SUPPORT OF

 ORPHANS IN THE KWAZAKHELE TOWNSHIP
- (iii) that the title page be amended to reflect as follows:

Supervis

or: Dr

RM van

Rooyen

Co-

Supervis

or: Ms EJ

Ricks

(iv) that the candidate should content theme the 4 case scenarios and this would then lead to the

problem statement;

- (v) that the research which has actually been done regarding the study, should be reflected;
 - (vi) that the section on saturation needs to be moved down to the Sampling Strategy;
 - (vii) that the opening question on page 20 be amended to read:

"Tell me about your experiences of living as an orphan in a township?"

- (viii) that rationale be provided as to why participants should have been orphaned for at least 6 months;
- (ix) that the Work Plan on page 31 needs to be unpacked into chapters and amended to include

2005:

- that it was suggested that the following sentence on page 25 be deleted:
 "However in the case of the choice of giving consent since a 14-year old female may give consent to the termination of pregnancy procedure."
- (xi) that the numbering method used throughout the proposal needs to be revised.

Yours sincerely



${f 1}$ OFFICE OF THE DEAN

FACUL TV OF HEALTH SCIENCES

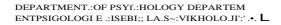
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ANNEXURE B

LETTER FROM ETHIC COMMITTEE





HUMAN ETHICS COMMITTEE

Dr RM van Rooyen Dept of Nursing Science MB 9th Floor UPE

Dear Dr Van Rooyen

RESEARCH PROPOSAL FOR ETHICS APPROVAL: S FRO OD

The proposal entitled *The livid experience of being an orphan in a township* was submitted for approval in October 2004.

The Committee accepted the proposal with the following amendments:

- •• On page 24 ethical considerations: researcher must specify how debriefing will be done and who the participant will be referred to.
- The researcher must specify how confidentiality will be ensured.
- No. 2.2 and 2.3 on the consent form specify the risks and benefits.
- The researcher must explain clearly how participants will be selected.

All amendments must be approved by the Supervisor.

Please inform the candidate of the outcome and we wish you well with the project.

Sincerely

PROF

POTGIE'!}

ACTING

CHAIRPERSON

В

Cc: Members of the Human Ethics Committee

Research Administration Office, UPE

Faculty Officer, Faculty of Health Sciences, UPE

UNIVERSITY OF PORT ELIZABETH/UNIVERSITEIT VAN PORT ELIZABETH/IYUNIVESITHI YASEBHAYI, PO Box 1600, PORT ELIZABETH, 6000, SOUTH AFRICA.

TEL: 041 5042354/5042776 FAX: 041 5833152. E-mail: yvonne.smith@upe.ac.za



ANNEXURE C

LEGAL GUARDIAN CONSENT

INFORMED CONSENT FORM FROM LEGAL GUARDIAN FOR MINORS

Sharron Frood, who is a Masters Curationis (M Cur) student from the University of Port Elizabeth, has requested my child, who is a minor to participate in a research study at this institution. The title of the research study is "THE LIVED EXPERIENCE OF AIDS ORPHANS LIVING IN A TOWNSHIP".

- o I have been informed that the purpose of this research is to assess the experiences of children who have become AIDS orphans and live in a township; to obtain insight and understanding into the nature of how they live with the purpose of making recommendation to Primary heath care nurse's related professionals and partners involved in caring for them.
- My child's participation will involve him/ her being interviewed by the researcher in his/her home and speaking about his/her experiences of living as an AIDS orphans in a township.
- I understand that my child is unlikely to benefit directly from participation as the research study will be carried out in order to make recommendations to primary health care nurses, related professionals and partners involved in the care of AIDS orphans living in a township. I understand that AIDS orphans living in a township in the future could benefit in the future.
- o I understand that my child can withdraw from the study at any time without any explanation being given to the researcher. It was explained to me that participation in this study is solely of a voluntary nature.
- I understand that the results of this research study may be published but that my child's name or identity would not be revealed. In order to maintain confidentiality of my child's records, Sharron Frood will assign codes to each subject's results and report in such a way that the participant cannot be identified.
- I have been advised that the results of the research study in which my child will be participating does not involve more than minimal risk.
- I have been informed that I will not be compensated for my child's participation.
- I have been informed that any questions I have concerning the research study and the participation of my child in the study before or after my consent will be answered by Prof van Rooyen, research promoter.
- I understand that at the end of my child's interview, time will be set aside for a de briefing session, from which a referral can be made to provide support to my child if needed.

- I understand that in the case of injury to earth myself or my child; if I have any questions about my child's rights as a participant in this research study, I can contact the Chair of the Advanced Degree Committee at the university.
- I have read the above information. The nature, demands, risks and benefits of the research study have been explained to me. I knowingly assume the risks involved, and understand that I may withdraw my consent and discontinue participation at any given time without penalty or loss to myself or to my child. I am signing this consent form, I ma not waiving any legal claims, rights or remedies. A copy of this consent for will be given to me.

Caregiver/Guardians	; Da	nte//200 official).	
and purpose, the	potential benef research study	its and possible ri have answered any	individual the nature sks associated with questions as fully as
Handbook of Good	Practice and Et human participal	thical Standards for nts. I have provided t	Medical Research: A Nursing Research to he participants with a
Signature	of Date	the / 2005	researcher

CHILD CONSENT FORM

IUnderstand that my legal guard	
has given permission(said it is ok)for me to take part in a research study	
Sharron Frood about the "LIVED EXPERIENCE OF AIDS ORPHANS LIVIN A TOWNSHIP".	/ING
I u understand that my involvement in the research study is voluntary and been told that I can stop participating from this study at any time, with out penalty and loss of benefit to myself.	
Signature of child.	
Date/ 2005	

ANNEXURE D

PARTICIPANT CONSENT

TITLE OF RESEARCH STUDY: The lived experience of AIDS orphans living in a township.

NAME OF THE RESEARCHER: Sharron Frood

DEPARTMENT: Nursing science 9th floor, University of Port Elizabeth tel 041 5042122.

DFECLARATION BY THE PARTICIPANT	SIGNATUTE
	OF PARTICIPANT
THE UNDERSIGNED(Name)	
Hereby confirm as follows:	
1. I was invited to participate in the above mentioned research study which is being undertaken by Sharron Frood, from the department of Nursing Science in the faculty of Health Sciences at the University of Port Elizabeth.	
2. The following aspects have been explained to me:	
2.1 AIM: The aim of the study is to explore and describe the lived experience of AIDS orphans living in a township so that primary health care nurses related professionals and partners can better care for ASIDS orphans living in a township	
2.2 Possible Risks: I will not be exposed to any form or risk or harm.	
2.3 Possible Benefits: As a result of my participation in this research study, primary health care nurses, related professionals and partners can become better informed bout the life of AIDS orphans living in a township and provide better care for them.	
2.4 Confidentiality: My identity will not be revealed in any discussion, description or scientific publications by the investigators.	
2.5 Voluntary Participation: My participation is voluntary. My decision whether to participate or not will in no way affect the current help and support I receive.	
3. No pressure was exerted on me to consent to participate and I understand that I can withdraw from the study at anytime, without giving any explanation.	
I HEREBY CONSENT VOLUNTARILY TO PARTICIPATE IN THE ABOVE MENTIONED RESEARCH STUDY	

Signed	
Date2005	
Signature of witness	
Date2005	

ANNEXURE E

COPY OF TRANSCRIBED INTERVIEW

INTERVIEW 1

R = Researcher

P= Participant

This interview was conducted with a 16 year old boy who lives with two friends in a two bedroom flat at the back of a shop in New Brighton Township Port Elizabeth. On arriving at the home to conduct the interview, I was approached by two men from the Shabeen next door, who were drunk and asking if they could help me. The participant was waiting for me at the gate to his home and her intervened. On entering the home I noticed that the furniture was sparse. In the kitchen there was a table and two stool's and two-ring hot plate. The participant showed me around the three rooms of the flat let. In his bedroom there was a bed and a cupboard where he kept his clothes. He wanted to show me the other bedroom but hesitated too. This was the bedroom of his mother when his mother was alive. In that room was a bed, TV and a cupboard. The TV was balanced on bricks. Two young men were asleep on the bed in that room, the room smelt of alcohol and Dakka. The participant informed me they were stoned and "sleeping it off". We went through to the kitchen sat on the bench and then the interview began. The participant has lived like this since the death of his mother. His two brothers live with His Aunt in Motherwell Township Port Elizabeth. He has been abandoned by his extended family.

R Can you tell me about your experiences of living as an orphan in a township?

It's too hard to me since my Mother she did die. I do know that day she did die too well. I just came back from the Transkei and I went to the Dora Ngienza hospital to visit her. I see her and she is very sick. When I saw her I became cross because she would not look at me. She was just lying there staring at the ceiling and she did not say anything. It was a Friday when I was at home with my 2 brothers and we received a phone call from the next-door neighbour saying that our Mother was sick. She was there at the hospital with her sister who was taking care of her. Her Sister did then bring her home that day and we did have her at home for a while. Then on the fifth day I came back from the Transkei, just two days after my Mother did come home from the hospital, I went to school. Then after school I saw her and she was dead now. I tried to talk with her but she not answers me she just looks at me and was staring at me. When I did come from school no one did tell me she is dead I just saw her like that when I went in to her room to greet her when I came home from school, that is how I did see her just dead in her room, (he points to the room that he now sleeps in the house) The neighbours were there just cleaning the room, going up and down. So I was shocked and no body told me, she had died and I went into the garage in my house. So I went and sit on my own there. My mother's friend then came to talk with me. She just said you have lost your Mum, just stay strong. She sit with me for a while and gave me a drink of water and sugar to lower my temper. And I just drink it but I didn't believe it. I feel too bad inside then.

R Tell me how did you feel when you knew she had died?

P I asked at that stage why? Why? Why did God take my mother, because she was my only hope? She has taken care of me my whole life as a single Mum and she has done it. I feel like I can't go forward and I feel angry to the world. I didn't cry I decided to wait to the funeral to cry.

R Tell me about the time from when she died until the day of the funeral?

P I was distressed because my family tell me that she will be buried in a week but that didn't happen. It took three weeks for the funeral to happen I was very distressed by that. My family supposed to come and stay for a week and then go back home but it didn't happen like that because we had no money. They did go home too early so on the funeral day it was just friends.

R Can you tell me more about this?

P The funeral it was nice because it was our friends. There were no family members because they return to their home, because they were here and she was not buried. She was not buried before because there were financial problems. It was my Aunt who made that problem because she says my Mother would be buried and the family came from the Transkei because she said so. S he was not right. So they returned to their home. They couldn't stay so long to the funeral because we had no money for food for them to eat. My Aunt did a wrong thing she should have waited to call them until we had enough money to make a funeral for my mother.

R Tell me about this?

P My family members could see we were distressed and struggling but they didn't say anything they just left and went home. I don't know why (he looks to the floor and shakes his head). I was thinking that they would help us but they didn't. They just went away didn't offer to help and left me to take care of my brothers. I am sure that they think my Aunt who took care of my mother would help but she didn't. My brothers were worried but they didn't say so, they just pretend that everything is ok I see them and I see they not ok.

R How did you feel about this?

P I just prayed. When my mother died this was a hard time to me. I had to feed my younger brothers so during this time I decided to take a job on weekends. I work for my Aunts sister from 7am to 9 pm. I was like a slave they gave me little money and I use that money to cook food for my brothers. No one take care of us; no one phoned to ask how are we are, nothing. I feel very angry with this because when my mother was alive she is taking care of them. She was a faithful person.

R Tell me about this anger?

P I just sit I have no words. If you want to survive in life it must be dark first then light so I just hold onto that.

R Can you tell me about other feelings you had at this time?

P I feel like the world is on my shoulders I felt so depressed I couldn't believe I had lost her. It was like I want to talk to her and she would not come. I played music and I think of her to take away the pain in me (he slaps his chest). My brothers cried at the funeral I did cry also. It was a hard time.

R Can you tell me more when you say it is a hard time?

P It was like I was dry inside. I had a sore think here (points to his chest) It was like something stuck in me and It wouldn't go passed my throat. It was too deep. When they buried her it was the time I cry. I don't visit my mother's grave because there is no tombstone so I don't know exactly where is she. But it is in Motherwell. I have no words to say it is just like that.

R Can you tell me about when you came home from the funeral?

P There were rumours in the family. They look at me badly because my father gave a cell phone when I was in the Transkei and the family say that now I think I am high class. I see this in their facial expression. I see they are jealous of me because I have a cell phone, I see they don't want to take care of me. He doesn't want to say anymore-other wise he will be disrespectful.

R Tell me how you took take care of yourself and your brothers when your family went back to the Transkei?

P I returned to school and it was nice because I have two friends. They were there but they are no longer there. They don't let me to think they just want me to play so that I forget. They also visit me at home. I still visit them now. I passed so I continue at school but they did not and could not go on because of financial reasons. But me I passed to go onto metric level. The thing that affects me the most was the shortage of food and also my mother's care. Because she always telling me what is good and not good. So I missed those ideas now, too much. My brothers were also sad and missed her too much they were here then but they are not here any more.

R Can you tell me more about this?

P My brothers are not ay my Aunts house. This is my mother's sister who was taking care of my mother when she is sick. She is in Motherwell. She is taking

care of them but I am not satisfied. They used to phone me and they tell me they don't feel at home there because there are many of them and my aunt is not like my mother my mother was a peaceful person but my Aunt she shouts. We were better here with my mother and we are closer to each other and we like each other too much in fact we love each other and they are gone now. I worry about them a lot it is my dream to take care of them when I get a job. I worry when I eat here at my home that they get nothing to eat at my Aunts place. My uncle who is staying there is also drinking Mchovalale (local beer made of yeast) he is not good for them. My mother was a good peaceful godly woman. When I have money I go there and I buy them socks. One of them only has shoes. They are my half brothers. They have a different father to me but we stay together when my mother was alive like brothers. I think of them as my brothers as we stay together our whole lives. The father of them he gives my Aunt money but she doesn't buy shoes to them. She doesn't use the money in an effective way. She gets money but she is not spending it on them. She is a traitor to me. I forgive her but I will not forget. I worry about my brothers. No one seems to care about me not even my Dad.

R Can you tell me about your relationship with your Dad?

P My Father, I have only known him for 2 years facially. I only discovered him last year. I went to the Transkei in 2003 for Male initiation my father says he would do everything for me. And when I returned here he says he would send me money and all of that so that I can carry on with my education and buy some food but he didn't do that now.

R How does that make you feel?

P It made me to feel very angry. I just ask myself I am his son or not! I ask myself that because he is not taking care of me. He doesn't send me any money at all nothing (he has tears in his eyes as he speaks and his voice tails off. He pauses for a while then he says). I don't know because I need money to live and he doesn't help me at all. What makes it worse is that he has a good job. He has never visited me and he never phones me. He gave me a cell phone when I visit him in the Transkei, all can do is to make a call back or if I have 2 Rand I will just phone him. He will phone be back but he is always making small excuses. He has told me that he was retrenched but I know that is a lie because he is lying every time. He is always making to me false promises. He has no fear that he can't keep his word to me. When I am near him he talking so nice. When I am far from him he just turns his back on me I don't know why. When I tell people I hate my father they do not understand. My Fathers mother seems like a nice woman, she also has a cell phone but she doesn't phone me. When I fist met her I was very happy because it was like my Mum talking to me (there is a long silence and he looks to the floor and shakes his head).

R Can you tell me about the support you have in your life?

P No body supports me (he cries and puts his head in his hands). I have no one to talk to when I have something that is making me to worry I keep it in my own heart. There is no one that I trust I will tell that person and he will makes some jokes about my situation. So I trust no one. Even the guys in my area they like to see how I am coping it 's like a test to see if I can cope in the situation I live ah but I am strong.

R Can you tell me about your relationship with these guys in the community.

P Ah I don't trust them. Some of them say this is not my home but it is my home. Then one guy he tell my Aunt that I beat him up and the Police came here to talk to me. She is a traitor to me. It was all lies that she did say about me. The police came here and I tell them that I didn't beat him. I will try to prosecute the Police because they didn't even get a statement. They just came and take me away by force I was unhappy about this. They took me away but they couldn't keep me. My friend came and he tells them the truth and I get out after one night. I feel the community likes to see me to suffer. There is one person my grandmother (My mothers mother). She is a woman who prays. I see her every day she encourages me and she believes in me. She loves me; she will give me oil and salt. But she can't support me, as there are other younger grandchildren she supports and she just has a pension. Because she loves me I know my life has meaning and I can keep my dream up.

R Can you tell me more about what gives your life meaning and your dream?

P I will say school also give me hope that I will find a good job one day. So I can improve myself and take care of my brothers. That is my only hope when I pass my Martic. School gives my life a purpose and my dream is to look after my brothers that is the only thing and also to be married.

R Can you tell me about any special relationships that you have?

P I have a girl friend but she is special. The one who was most special to me was my Mother she was my role model. She was a good woman.

R Can you tell me about your relationship with your girlfriend?

P She is at school. I see her every day we hang out together every day. She loves me; I think she is special to me. She doesn't comment about my life that's why I love her. She is not looking at what I do not have she just loves me. I have a sexual relationship with her but I do not love it. I use condoms all of the time, I think it is the right thing. She love it and she make me to feel safe but I don't like it all of the time I don't know why. Sometimes I feel empty in side like a hole it is sometimes sore like when I am hungry because I don't eat

R Can you tell me more about how you feel when you don't have food to eat?

P Um, it like I feel weak and I don't want to talk so much to people. I just sit alone and think and think and think. Maybe when I don't find something to eat I just go alone and sleep and sleep and sleep.

R Can you tell me about the things you think about?

P Yes I think of my mother and I think if my mother was still to be here I would not be hungry. I just think if someone was to give me something I will just to cook it nicely and then it will be better for me. I smoke Dakka when I am high I am not hungry, when I wake up from smoking Dakka I am too hungry its terrible.

R Can you tell me more about smoking Dakka?

P I smoke it every day when I am coming from school. I don't smoke it in the evening time because I am going to school in the morning and my head must be clear. It makes me to be peaceful but it's too expensive to me.

R Can you tell me more about why you smoke Dakka?

P Yes it is 5 rand for a joint but when I am having 5 rand I maybe buy half a loaf of bread and there is nothing I can afford to eat so maybe I am left with 2 Rand and then I go to my they guys selling Dakka. Ah they know my situation and they give me a joint for 2 rand, they accept that. They know my situation and sometimes they will not even take the 2 rand they just give it to me. I never have to pay them back. I smoke it because when I smoke it I go to another place a place of peace and I do like that place.

R Can you tell me how you feel when you smoke Dakka?

P it makes me feel humble, like quiet just thinking, I don't talk so much it makes me to be quiet and it's nice. It makes me to feel peaceful. When I am not smoking Dakka a feel agitated but when I smoke it takes me away from here to another place where I am quiet and not worried. It makes me to feel better than the feelings I am having every day when I am at home on my own.

R Can I ask you to tell me about the feelings' that you have every day?

P I say I am fine; I mean I pretend to be fine but I am not fine. I feel a lot of things in my heart, like what am I going to do wear am I going to get food, I ask myself why me? Why does no one care about me or want to take care of me. I miss my mother and I am angry that God took her. I wish sometimes I had never been born.

R Can you tell me more about that?

P Yes I wish I had never been born because of the entire thing that have happened to me and my family members are not here now and everything is just being up side down. My father is not supporting me and I just think like I am just coming from the water and not coming from him. That makes me to be embarrassed that no one is taking care of me. My Father he didn't give me love. When my friends are talking about their fathers and saying good things I will lie and tell them he gives everything to me. I do that because I don't want them to find out the truth. Sometimes I don't know how I manage my life. Some days I don't eat. I remember in February I didn't eat for 4 day's. Even at school I do not eat. Even then if it raining as well there is something inside that makes me to go to school. When I am at school I am just thinking of school and nothing else only school. If I am doing history at school then I am thinking of history and nothing else. If I am in school then my mind is in school. The thing I don't like is to come home from school when there is no food in my home to eat.

R Can you tell me how you feel when it's the end of the school day and you are going home?

P It becomes boring because I know that I will have to come and cook if I have foods to cook and if I have no food then there is nothing to cook and then I become hungry and I do not like to be hungry. If I did not have school to go to I would be bored all of the day. My only thing that I like is to go to school so that my mind is busy on my studies. If there is no food to eat then I am going to lie on my bed to sleep. Then when I wake up I am going to my neighbours to find something to eat if I am not finding something then I just drink some water to fill me up then I am going to sleep at home. At the weekends I must go to my friend's houses and see if I get something to eat. It's better to be with them than to be alone in my home without food.

R Can you tell me more about the weekends?

P I stay outside and sometimes smoke and then go to my friends to watch TV. The one thing I am not doing is going to taverns because I do not like it when people are fighting. I will just watch TV at a friend's house and then come home. I don't like to come home when there is no food to eat. Sometimes I go to church. I liked to go to church when my mother was alive but now it's different. I don't really like to go top church because I am not having the correct clothes to wear and I think people they look down at me. Sometimes I watch soccer in the Township on the Saturday afternoon: I like that because when I watch soccer I am not thinking about my problems. In the evening time I watch TV with my friends and smoke Dakka. One thing I am not doing is going to the taverns. When my mother was alive it was not like this it as different. I liked to be at home with my mother and my brothers helping her in the home and being with her. She was so caring and encouraging. Now that she is not at home and my brothers are not there I don't like always to be there. My mother always she encourages me not to go to the taverns because she didn't want me to fight. She knew I smoked Dakka when she was alive she didn't like it and I didn't do it too much. The thing that makes me to smoke Dakka more is when brothers do come to visit me and then they do go back to my Aunt I miss them too much.

R Can you tell me about the last time that you saw your brothers?

P I miss them too much but I don't like to go to my Aunts home where they are because the last time we argued and I didn't like that. We argued because I told her that one needed new shoes for school and why did she not buy them for him? She said it was none of my business and became angry. I wanted to shout at her because she is a traitor but I just keep quiet and then I go to my home. One weekend my brothers came to see me because they also miss me. So it was good because they come to me at the right time. When they came I was cooking so they had a meal with me. I was cooking chicken and I dish for them and we were very glad and I feel proud to take care of him. I feel proud when I can help my brothers because I love them. My Aunt she takes them away from me (his voice tails off and he looks down to the floor). I feel angry about that I say that I will forgive her but I will never forget what she did to us. She is so bad and has made my life to hurt. I have no words to say the pain I sometimes feel. I feel bad because I miss them I was so used to them being here. She was saying that I would not be able to take care of them. But they both had child support grant and that money is helping us to buy food. She has taken all of that away from me. I was also dependent on the money they received through the child support grant. I don't know why no one came to take care of me because I am still young and I need support (he is silent for a long time) but I have hope that I will still succeed. I wish to have the power to do a good job so to take care of my brothers. Know I can take care of them because I take care of my mother when she was sick.

R Can you tell me more about this?

P Yes I would cook for her when she was resting in her bed. She used to like soup and I used to feed her. Then I was afraid when I did this because I knew she was going to die. She never told me she had HIV but I knew that what it was. My mother was getting sick in 2002 that is when our lives did change. She used to get sick then go to the hospital then she was too weak when she returned home when she did get strong. Then she would make us breakfast and lunch to go to school but it made her tired so she would sleeping the afternoon so that is why I cook for her. She told me at this time that I was to look after my brothers. That was the only thing she said and that we must keep on going to school. It was still nice then because I am not going outside every day and I am just to be at home with her listening to her and having jokes with my brothers and we were laughing. We used to sit on the bed with her and we used to watch TV with her and talking-to her (he has tears in his eyes now). It was a nice time it was a good time to be with her, a good time.

R Can you tell me what makes you feel good about life now?

P Diane (research PhD student from Holland) made me to feel good because she listen to me. My dream to care for my brothers and to be married makes me to go on in life that's all. MY relationship with my girl friend also makes me to feel good. When I am bored I go to her and we make some jokes. When she holds me I feel emotional. She make me feel like I am wanted and accepted and it makes me to be tall. I think about her and she thinks about me too and I like to talk with her. I feel safe there when I am with her. I also do feel safe to my teachers because they do motivate me to my dream

R Tell more about the relationship you have with your teachers?

P They did not realise I am staying alone and they just look at me the same. They don't understand my problems. For example in the week there is that thing where we must bring 2 rand to buy cleaning products for when we clean the classroom. They know I don't have 2 rand so when they ask and I say no they just shouting at me and I don't like that it makes me to feel so small. They tell me off because they say I don't want to participate but I do want to but I can't pay them. When they shout at me I just look at them but I do not answer. I feel small also that I can't pay school fees and I don't have a uniform. But I am glad that I can have education and I focus my mind on my studies. Some of the children at school they make fun of me because they see that I don't eat at school and they say to me you will fail because you are getting weak. When it is break time I will not go out of the classroom because I don't even have cents to buy an apple with. So I am just staying in the classroom relaxing. Its better to do this and not to be hateful. I know that I will not die. And one day I will be a man and then I wont feel small.

R Can you tell me more about this?

P This thing of not having my initiation worried me too much. The friends in the community they look down to me. What going on they say he is not a man yet. In my mind I just think I am not supposed to be a man yet anyway. It is common in the Township for male initiation to be delayed because of financial problems. The funning think (he laughs to himself) they think I am a man because I do return from the bush and I am so fat, they don't know my clan too well so I trick them in to thinking that I am a man. So I have the advantage. I only tell them after 2 weeks of my return that I am not a man and now they are not sure so I still have the advantage. They think I am a man because I have been to the bush. They also think I am a man because I live alone in this house. I felt proud and strong that they think these things about me. Some people in the community who stay close to my house they are always encouraging me because they think I am strong and they tell me to stay strong. The things that make me to feel small are the punishments from school in my community I am proud because they do think I am a man. It is in Dec 2005 that I go to the bush for initiation.

R Can you tell me more about the punishments from school that make you to feel small?

P Yes when you are late for school you have to pay money, but when you don't have money which is 50 cents to pay at the gate, or you don't have it you will be punished. That is they smack you on your hand, ah I have had it too much. The 50 cents get paid to student on the gate who is representatives of the Student Representative Council. It's the principal gives me a smack on my hand its too sore. He says if you don't want to get that you must get up early. I tell him I am living far away and that I stay alone. But I love school because to have knowledge is good to me. So I do put up with it because one day I will have a job when I do get my education. The other thing that is making me to feel small is the day to my birthday.

R Can you tell me about your birthday?

P I just accept it my birth date. If have, a few cents I make something to eat. I know that I used to have birthday because my mother she used to do one for me. Now I think there are those that never had a birthday but I am glad that I am having the chance before to have a birthday. I think in my life I had 5 times when I have a birthday, so I am still glad for that chance that I had. When my mother was alive it was different. She used to make my birthday too nice for me. She used to make me a cake and buy me a trouser for me or give me some money. I like it too much then because she was not working and she sacrifices for me to make it a birthday. I know she love me because she sacrifice for me. She was trying very hard to make it a good day to me. I loved the way my mother she used to care for me it was a special love. She use to think of other people before herself and that what made her to be special. She used to help her sister a lot that is why I feel so betrayed by my aunt because my mother did a lot for her when she was alive. Today it is my brother's birthday and I am taking for him a cake because I don't want him to think his birthday is not important, because it is. Important. I am glad to you Sharron to take a cake to him today as it make me to feel too proud and it will be too special to him also(I took a cake because he asked me to and after the interview we took it to his brother in Motherwell). This is a good thing to me and makes me to be inspired like my friend at Rhodes University

R Tell me how your friend who is at university inspires you?

P See he is like a light to me because he was from here now he is to the university there is Graham's town. He tells me he needs me to be there too. He thinks that I can make it and that encourages me to also try hard because it is possible for me too. We were in the same class and I am as good to my school as he is. I also like history like he does. If it's possible for him it is for me too. So I know it is also possible to me if I am working hard too. That is why I like to learn and love school because my only hope is to get a good education. That is my focus and I don't like the thing that pulls me away from my focus.

R Can you tell me about things that pull you away from your focus?

P Yes I can first of all, it was like there was something from a friends house that I want to steal I did steal it because it was clothes I wanted and it did give me status in the community, I was worried though that I would be caught and then I will miss school and I will lose the focus of getting an education. So I don't steal anymore. If I didn't go to school I would feel lost because it is good to me. I went to court and they punished me I do correctional service after school for 6 months. It was a hard time. I was at Empliwene (TB hospital) and I clean it, it was too terrible. No I will never steal again I don't want to do anything wrong again. Because I know my focus is to get an education then I am not letting anything to take away my focus. I do not want to be useless in my life. My brothers are important to my cousins and me also. It's important to me that they can be proud of me. I don't want to waste my life. I want to get a good education, a good job, take care of my brothers and to be married.

R Can you tell me about how you felt that day your brothers went to live with your Aunty?

P They were staying with her when I went to that Transkei, but I didn't know that they were going to continue to stay with her. I was shocked when I came back from the Transkei to find they were still with my Aunt. I had a discussion with her after the funeral of my mother and we disagreed and I just left the house. I was scarred because I never lived alone before. I was afraid I had no body to talk with at all and I am worried about who will take care if me. I miss them because we were talking all the time now they are not there. I used to sleep in the same bed as them. It was the first time for me to sleep alone and I did not like it. In those days I was lonely so I went to watch TV with friends home I didn't like to come home because I miss them too much. There was no food for me to eat then. My friend used to share his supper every night. He was washing cars in Summer strand and he gives me money to buy milk and bread. In those days I wish I was also dead I felt like I lost everything and I was sad. I knew I had to face it so that is why I stayed. I tell myself there is nothing I can do so I just continue in my life and I go to school. I used to cry sometimes, even when there were no tears I used to cry out why. Losing my mother was the lowest think for me. I know God let it to happen for a reason and I can cope in my life because I am strong. I am still alive and so I am having hope. I just want to live my dream. I learnt that the hard time is difficult but that some light has come and my focus on my dream does make me to be strong