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**NEEDS OF CHILDREN AFFECTED  
BY HIV/AIDS: MANGAUNG IN THE  
FREE STATE**

**BY**

**ROSEMARY MOLIEHI CHAKALANE-MPELI**

# **NEEDS OF CHILDREN AFFECTED BY HIV/AIDS: MANGAUNG IN THE FREE STATE**

**BY**

**ROSEMARY MOLIEHI CHAKALANE-MPELI**

A dissertation submitted in accordance with the requirements for the

**Masters Societatis Scientiae (M.Soc.Sc.Nursing)**

**In the  
Faculty of Health Sciences  
School of Nursing**

**At the  
University of the Free State**

**STUDY LEADER: Dr. Lizeth Roets**

**November 2004**

Universiteit van die  
Vrystaat  
BLOEMFONTEIN

22 AUG 2005

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I declare that the dissertation submitted for the degree, Magister Societatis Scientiae in Nursing to the University of the Free State is my own independent work and it has not previously been submitted for a degree to another University/Faculty. I further more cede copyright of the dissertation in favour of the University of the Free State.

.....*R.M. Chakalane-Mpeli*.....

**R.M. Chakalane-Mpeli**

## ***THIS RESEARCH IS DEDICATED TO:***

---

- My mother; 'Mathapelo Celestina Chakalane. I managed to be where I am because of your never ending prayers. While I was still young, I used to say you are too religious, but now I see and I do acknowledge your prayers. This is the example I will set for my children;
- My family; Matsatsi, Mohlomi and Thaele. You were there when the getting gets tough, and the tough get going;
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- My late father, Keizar Emmanuel Chakalane. I got this type of personality from you, and I know today you were going to be a proud father.

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---

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# CHAPTER 1

## *Introduction and problem statement*

---

### 1.1 INTRODUCTION

The Sub-Saharan Africa, of which South Africa is part, is known for its poverty and tribal wars, but currently the Human Immune Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) epidemic is the latest crisis. According to Dorrington, Bourne, Bradshaw, Laubscher and Timaeus (2001:3), 21.8 million people in the entire world have died due to HIV/AIDS since the beginning of the epidemic, and 80% of all deaths occurred in Sub-Saharan Africa. If the present trend continues, the future will be dark for many children whose future is already bleak because of the above-mentioned problems.

Yet, as shocking as these death rates may be, a disastrous effect of AIDS is the vast number of children who will watch as their parent(s) slowly become sick and ultimately die. According to the Joint United Nations Programme on HIV/AIDS [UNAIDS], the United Nations Children's Fund [UNICEF] and the national Black leadership on AIDS (1999:1-3), more than 90% of AIDS orphans are in Sub-Saharan Africa, and these numbers are increasing daily. According to Smart (2000:16), AIDS orphans are estimated to comprise 9 to 12% of the total population of South Africa by 2015.

With the strategic use of antiretroviral drugs by pregnant HIV mothers, at least 70% of children will be born without the virus (HIV). These children have a 100% chance of being orphaned, and added to these will be children born to the mother before she became infected with HIV (Whiteside, 2000:14-15). As cited by Kerkhoven (1998:4-5) and Loudon (1998:5-6), Sub-Saharan Africa will be raising the orphaned generation in the face of already weakened



societies because of social and economic problems as well as underdevelopment.

The numerous consequences of the AIDS epidemic will then demand a proactive and coordinated approach, based on proper analysis and prioritisation of needs of the affected children. Children may be affected in various ways: they may be abandoned or orphaned as a result of AIDS, may be from an HIV infected family and vulnerable to becoming HIV infected; or may be from an uninfected family in an affected community (Smart, 2000:19).

## **1.2 INTRODUCTION TO THE PROBLEM STATEMENT**

### **1.2.1 Impact of AIDS on children**

The AIDS orphans and children of terminally ill AIDS parent/s are extremely vulnerable children, who may suffer myriads of problems that can have a lasting impact persisting into their adulthood. The illness and death of their parents will leave them devastated, with no one to cater for their specific needs. If these needs remain unmet or inadequately met the following will become apparent:

- Increased mortality and morbidity.
- Physical and psychological underdevelopment.
- Delinquency
- New high risk groups, vulnerable to HIV infection (Foster, 1997:4-5; Loudon, 1998:5-6; Smart, 2000:24; Wekesa, 2000:12-14).

Children will be affected in various ways, one of these manifesting in physical problems.

### **1.2.1.1      *Physical problems***

HIV/AIDS affects children long before the death of their parents. As there is lack of attention to the emotional, physical and developmental needs during the parent/s illness and death, the children may become predisposed to high incidences of infectious diseases, mortality rates and poor levels of nutrition (UNAIDS *et al.*, 1999:1-3).

In developing countries, mothers are considered as primary health care workers since they can easily see if there is any thing wrong with a child. Again, if illness or death strikes the mother, the caregivers may not respond to the ailments of the child early enough, and/or may even neglect good nutritional practices, hence malnutrition may occur. The child's immunisations may be ignored; hence children may be predisposed to preventable communicable diseases like polio, measles and tuberculosis (Foster, 1997:4-5). The issues of physical effects do not happen in isolation when a primary caregiver is either ill or dead, but in addition, children will also need a place to stay or somebody to look after them.

### **1.2.1.2      *Residential problems***

The traditional model of surrogate childcare, in which the extended families have to absorb the orphans, remains questionable because of the increasing number of AIDS orphans that are to be adopted or fostered into the family that already have other children. These very families and communities that are expected to respond to the plight of AIDS orphans are also faced with the social and economic problems that prevent them from total commitment in the caring of these children affected by AIDS (Kerkhoven, 1998:4-5).

Besides the family's social and economic problems and the increasing number of AIDS orphans, there are issues of culture in the black communities that do not fit in well with western practices of fostering children. Fostering in the African societies is only acknowledged if the couple is childless; hence less emphasis is placed on the needs of the child but on the needs of the childless couple (Harber, 1999: 9-10).

***With the relentless toll of HIV/AIDS, fuelled by poverty, prejudice and ignorance, the ability of the families and communities to support these children will be reduced; hence the following troubling scenarios will occur:***

#### **1.2.1.2.1 Grandparent/s caring for the orphans**

At this time of their lives one would expect them to be recipients of care. Instead, the very old and probably very poor people, have to struggle to raise these children with their meagre government grants. According to Foster (1997:4-5) the average age of grandparents recruited into childcare is 62 years. At this age and with their economic problems one could expect serious implications for child health.

#### **1.2.1.2.2 Households headed by children**

According to UNAIDS *et al.* (1999:1-3), children who often become heads of households are of primary-school age. Not only are these children deprived of parental care and nurturing during the parent/s illness and death, but they also have to act like adults by looking after young siblings. These children are not only engaged in household tasks like supervision and care of younger siblings, but have to take care of parents who are sick and dying. In such households basic and social needs are largely inadequate because of the immaturity and lack of experience of the caretaker. Many may quit school and jeopardise their own health and developmental needs in order to take on roles as parent, nurse and provider.

#### **1.2.1.2.3 Children without shelter**

Commenting on the AIDS orphans' situation, Loudon (1998:5-6) reports that the children's formative years will be shrouded in uncertainty, as they will be shunted from one relative to another, and many will be raised by strangers. Young children are likely to be abandoned, and this is particularly inevitable if parents are dead and an extended family is faced with a vast number of orphans (Smart, 2000:22). Without shelter, education, work skills or family support many will end up living on the streets. As literature indicates, children living on the streets have poor access to basic needs, and in many cases these children often lose their dignity and human rights. Street children are easily drawn into crime and selling of sexual favours because of hunger or a need to belong, and this can predispose them to HIV infections (Smart, 2000:31-32).

#### **1.2.1.3 Emotional needs**

Literature indicates that emotional needs are: the need for love and security; need for new experiences; need for praise and recognition and the need for responsibility (Pringle, 1975:148-149). With the death of parent/s, lack of affection, insecurity and loneliness are inevitable.

#### **1.2.1.4 Stigmatisation**

Families frequently experience abandonment and social isolation if the diagnosis of HIV/AIDS is made known publicly. The lack of knowledge and understanding born out of stigma, discrimination and fear regarding the nature and transmission of HIV/AIDS have denied most children access to education and health care services (UNAIDS *et al.*, 1999:1-3). As a result most parents and caregivers do not disclose the HIV diagnosis to the children lest he/she becomes isolated or rejected by the peer group or service providers (Ledlie, 1999:141-148).

It has been identified that people with HIV/AIDS force themselves into isolation because of embarrassment and humiliation, while the society will abandon them with a connotation of potential harm. This is ultimately reflected onto the children affected, as they will also be isolating themselves or be discriminated against by other children (Zerwekh, 2000:47-60).

The fear that still surrounds people with HIV/AIDS and their families has built a wall that prevents the communities from recognising the impact of AIDS on children, especially in families where the integrity of the family has been threatened by the economic stress (Zerwekh, 2000:47-60).

#### **1.2.1.5      *Economic crises***

Many communities that are severely hit by the HIV/AIDS epidemic are already disadvantaged. Poverty and poor infrastructure [little or no access to essential services] are characteristics of these communities (Kerkhoven, 1998:4-5). These conditions are conducive to the rapid transmission of HIV, and individuals mostly affected in South Africa are the black and the poor (Harber, 1999:6-8). Besides being poor, the income of the HIV infected parent becomes reduced due to loss of earnings, because of repeated sick leave and the high medical expenditures (Foster, 1997:4-5). If the parent dies, the funeral expenses further deplete the resources, and the children will then be plunged into an economic crisis and insecurity (Smart, 2000:22, Wekesa, 2000:12-14).

Owing to the total loss of income, children in these households are at the increased risk of malnutrition and ill health. They will not be able to afford costs of transport, consultations or medicines and thus cannot access the basic needs of survival. Cullinan (2001:15) reported in the Sunday Times news paper that children in some schools in rural KwaZulu-Natal are being sent away from school because they cannot afford to buy uniforms or pay school fees.

#### **1.2.1.6      *HIV status of the child***

In describing the facts about children affected by HIV/AIDS, literature indicates that some of the children may be infected by HIV/AIDS through vertical transmission and sexual transmission (because of the roles children fill as poor, hungry, exploited and abused human beings) and also through unsafe cultural practices as in the case of scarification and circumcision (Smart, 2000:19).

### **1.3      PROBLEM STATEMENT**

There are various ways in which children can be affected, and this can limit the possibility of a successful childhood, which in turn could affect their future as productive members of the community. Several studies have shown that the need for caretakers of infants and very young children is obvious and immediate as a matter of basic survival. However, the needs of older children (approximately 8 to 18 years of age) can be easily underserved, overlooked or underestimated because the risks to their survival are less apparent (Lyons, 1998:6).

In the light of many problems that surround children affected by HIV/AIDS, and also in the light of promoting children's participation in democratic decision-making, it is of the utmost importance that these children be given an opportunity to express their needs, so that the institutions and the systems that serve them can improve the efficiency of their services, based on better knowledge and understanding of these children's needs.

## **1.4 THE PURPOSE OF THE STUDY**

The purpose of this study is:

- To identify and describe the needs of children affected by HIV/AIDS
- Based on the needs, to give recommendations to the public service providers and organizations that assist these children.

## **1.5 DEFINITION OF CONCEPTS**

### **1.5.1 Needs**

A need is some state of affairs that if present, would improve the well-being of an organism. This may be something basic and biological or it may involve social and personal factors and derive from complex forms of learning (Reber, 1995:484).

### **1.5.2 Illness**

This is an abnormal process in which aspects of the social, physical, emotional, or intellectual condition and function of a person are diminished or impaired, compared with that person's previous condition (Mosby's dictionary, 1986:568).

### **1.5.3 Children affected by AIDS**

Smart (2000:19) indicated that affected children are those children who may be abandoned or orphaned as a result of HIV/AIDS. They may be from an HIV infected family, they may be vulnerable to becoming HIV infected or they may be from an uninfected family in an infected community.

*For the purpose of this study an affected child will be a child between the age of 11 and 18 years who has lost his/her parent/s to AIDS or whose parent/s is/are ill due to HIV/AIDS.*

#### **1.5.4 Pre-orphan**

According to the World Bank and UNICEF (2002:2, 6) a pre-orphan is a child who has not yet lost a parent to HIV/AIDS, but nonetheless, who is caring for their terminally ill parent.

*For the purpose of this study, a pre-orphan will be a child between the age of 11 and 18 years, who has not yet lost a parent, but is caring for a terminally ill parent due to HIV/AIDS.*

#### **1.5.5 AIDS orphan**

According to UNAIDS (1999:5) and Smart (2000:iv), an AIDS orphan is defined as a child who has lost his/her mother to AIDS before reaching the age of 15 years.

*For the purpose of this study an AIDS orphan will be a child between the age of 11 and 18 years who has lost one or both parent/s to AIDS.*

#### **1.5.6 Community**

A community is a collection of people who share some attribute of their lives. It may be that they live in the same locale, attend a particular church, or even share a particular interest such as painting (Kozier, Erb, Berman & Burke, 2000:195), while Vlok (1996:6-7) defined community as a group of interacting individuals who occupy a certain territory and who are united by commonly shared beliefs, values and norms



## **1.6 RESEARCH DESIGN**

Since the purpose of this study is to explore and describe the needs of children affected by HIV/AIDS, the appropriate design will be explorative, descriptive, and contextual within a qualitative paradigm. This design is selected, because the aim of a qualitative research design is to understand the human needs from the totality of their life ways, bearing in mind the dynamic interplay of these life ways, with the social, economic, political, religious, and cultural values within the historical and meaningful life events (Burns & Grove, 2001:65; Leininger, 1985:21-24).

## **1.7 RESEARCH CONTEXT**

This research will be confined to children affected by HIV/AIDS; either as pre-orphans or as orphans. They must be permanently staying in Mangaung in the Free State. The children must meet the inclusion criteria and must also agree to participate in the study.

## **1.8 MEASURING STRATEGY**

A phenomenological perspective will be adopted with the use of in-depth/unstructured interviews. The interviews will be conducted with the children until saturation of data is reached. This perspective is suitable for this study, because it is a process of learning and constructing the meaning of human experience through intensive dialogue with persons who are living the experience (Lobiondo-Wood & Haber, 1997:262).

Unstructured interviews seem to be the best way of identifying the needs of children affected by HIV/AIDS, as these types of interviews provide in-depth information about the phenomenon, and can be used for people who cannot read or write, while non-verbal messages can also be observed and interpreted. The great advantage of this type of interview is its flexibility, which

allows the researcher to explore greater depth of meaning than any other technique (Burns & Grove, 2001:420-421).

The researcher has neither the skill nor the experience to conduct the interviews with children, and for this reason, a field worker will be used to conduct the interviews. However, the researcher will be present during the interviews, for the purpose of fieldnotes.

**The central scheduled question of the interview will be adopted to fit the individual child's situation:**

For the pre-orphan child the central question of discussion will be:

- **Can you please tell me if there is something in your life in general that is lacking since the illness of your parent/s?**
- **Please tell me more about your needs.**

For the orphan the question will read thus:

- **Can you please tell me if there is something in your life in general that is lacking since the death of your parent/s?**
- **Please tell me more about your needs.**

All the interviews will be recorded using an audiotape per subject's consent or the consent of the caretakers, and they will be transcribed into English as soon as possible after the interviews. The names of the subjects and their next of kin will not be tape-recorded for reasons of confidentiality. Numbers instead of names will be used as references to represent the subjects (for an example subject number 1). The interviews will be conducted in Sesotho, Xhosa, and Tswana as preferred by the subject. The interviews will be conducted at the homes of the subjects where they were confronted with the plight of HIV/AIDS.

## **1.9 UNITS OF ANALYSIS**

The units of analysis in this study will be children in Mangaung whose parents are terminally ill or who have died due to HIV/AIDS. The inclusion criteria into the study will be based on children:

- between the age of 11 and 18 years, as at this age their cognitive development will allow them to be more aware of their needs; as at this age their operational thinking allow them to develop hypotheses about possible outcomes of problems and evaluate these outcomes comparatively (Pawlik & Rosenzweig,2000:256-257).
- who are able to speak and understand either Sesotho, Xhosa, or Tswana;
- who are residing in Mangaung;
- who will be expressing willingness to participate in study;
- who are either paternal or maternal orphans, or both; or
- whose parents are ill due to HIV/AIDS;
- whose parents or caregivers give consent to participate in the research

## **1.10 SAMPLING**

Naledi Hospice (Formerly Bloemfontein Hospice) is a place that deals with home-based care programs and also assists in the care, support and placement of AIDS orphans. The subjects in this study will be recruited from the community through the help of the Hospice personnel. A convenience sampling method will be adopted to recruit subjects into the study. As indicated by Burns and Grove (2001:374), convenience sampling is an approach that provides means to conduct studies on topics that could not be examined using probability sampling.

## **1.11 PILOT STUDY**

For the purpose of the pilot study, two (2) children will be recruited from the Mangaung community through the help of Naledi<sup>1</sup> Hospice personnel (the Home-based care worker). One child must have lost parent, and the other child must have a parent who is ill due to HIV/AIDS. Children who participated in the pilot study will not be included in the major study. The focus of this pilot study is to test whether the research questions are clear and understood by the subjects. Furthermore, the results of the pilot study will be used for modification in an effort to refine the question and methodology, so as to ensure success of the major study (Burns & Grove, 1997:790).

## **1.12 DATA COLLECTION**

The researcher will make use of a field worker to interview the children, while the researcher will be responsible for field notes. Data will then be collected from children who meet the sampling criteria. The interviews will be conducted at the homes of the subjects where they were confronted with the plight of HIV/AIDS. The caregiver will have to give a written consent before commencing with the interviews. Interviews will be conducted in languages preferred by the subjects, and will continue until saturation of data is reached, this being when no more new information is given. However, the interviews will be done in such a way that an individual child's needs will be accommodated, i.e. each child's concentration span will be taken into account and where necessary, a second interview will be rescheduled. These interviews will be tape-recorded per subjects' and caregivers' consent and these will then be transcribed as soon as possible. During the interviews, non-verbal cues of the subjects will be observed and recorded as field notes.

---

<sup>1</sup> Formerly Bloemfontein Hospice

### 1.13 DATA ANALYSIS

As indicated earlier on, the interviews will be transcribed into English as soon as possible after each interview.

The transcribed tape-recorded interviews and the field notes will be analysed using Tesch's method (1990) as cited by Creswell (1994:154-155). This method provides the following steps that will be used in the analyses:

- Get sense of the whole by reading through all of the transcriptions carefully, and write down the ideas as they come to mind;
- Pick one most interesting interview; go through it, asking yourself: what is this interview about? Do not think about the substance of the information, but rather on its underlying meaning. Write thoughts in the margin;
- After this task has been completed with other interviews, the list of all topics will be made. Cluster similar topics together. Form these topics into columns that might be arranged as major topics, unique topics and leftovers;
- Now take this list and go back to your data. Abbreviate the topics as codes and write the codes next to the appropriate segment of the text;
- Find the most descriptive wording for your topics and turn them into categories. To reduce the total list of categories, group together the topics that relate to one another. Lines may be drawn between the categories to show interrelationships;
- Make a final decision on the abbreviation for each category and arrange these codes alphabetically.

The data materials belonging to each category will then be assembled in one place, and a preliminary analysis will be performed.

Open coding will be used, in which an independent coder and the researcher will locate themes and assign codes in an attempt to convert data to a smaller, more manageable and more manipulative units that will be easily retrieved (Polit & Hungler, 1995:522; Neuman, 1997:422).

The researcher will give an independent coder, experienced in qualitative research the raw data of the transcribed tape-recorded interviews and the field notes, as well as the Tesch (1990) method of data analysis as cited by Creswell (1994:154-155). After analysing independently, the two will then meet to discuss and reach consensus on the analysed data.

If necessary, re-coding of data will be done with a view to capturing the essence of needs being studied, and also to identify other constituent parts of the needs (Tesch, 1990: 97; Creswell, 1994:155). The results will then be given to two of the research subjects to confirm whether the needs are truly reflected.

#### **1.14 MEASURE TO ENSURE TRUSTWORTHINESS OF THE RESULTS**

Validity in qualitative research is concerned with the accuracy and truthfulness of the findings (Brink, 1997:124). Guba's model, as pointed out by Streubert and Carpenter (1995:25-26) will be used to ensure reliability of the results. The model identifies the following criteria in assessing reliability.

### □ ***Credibility***

This establishes the truth of finding, as viewed through the eyes of those being observed or interviewed, and within the context in which the research is carried out (Brink, 1997:124). Prolonging the time with the subjects, hence gathering more information will ensure this criterion. The results will also be given back to the subjects to confirm whether what will be written truly reflects their needs. Furthermore, the supervisor/study-leader, who is experienced in qualitative research, will also evaluate the results.

### □ ***Dependability***

Dependability refers to whether the findings would be consistent if the inquiry were to be replicated with the same subjects in a similar context (Streubert & Carpenter, 1995:26). This will be ensured by providing an explicit method as to how data will be collected, analysed and interpreted. Furthermore, an independent coder will be used.

### □ ***Confirmability***

Confirmability refers to the guarantees that the findings, conclusions and recommendations are supported by the data, and that there is an internal agreement between the researcher's interpretation and the actual evidence (Brink, 1997:125). The researcher will ensure this by using bracketing and intuiting principles during the process of data collection and data analysis. According to Brink (1997:125), if the other three criteria of reliability are achieved, so will be the confirmability criterion.

## □ ***Transferability***

Transferability refers to the probability that the findings of the study will have meaning to others in a same situation (Mayan, 2001:10; Brink, 1997:124). This will be ensured by selecting the sample and a context from which much can be learned about the phenomenon of interest; hence a convenience sample will be used.

### **1.15 ETHICAL CONSIDERATIONS**

As this is interactive research, ethical issues will have to be considered. Prior to data collection, permission will first be requested from the Ethics Committee of the Faculty of Health Sciences of the University of Free State and the Directors of the Bloemfontein Hospice, as well as from the caregivers of the affected children and the children themselves.

The researcher maintained the ethical standards appropriate to this study (see a complete description in Chapter 2)

### **1.16 VALUE OF THE STUDY**

According to the researcher's knowledge, studies about the needs of children affected by HIV/AIDS have been large-scale studies based on quantitative data. Thus some of the children's needs may have gone unnoticed, as they did not have an opportunity to spell out their own needs. There may therefore be a credibility gap between what other people see and what the affected feel. Based on the fact that no single skill or knowledge of one particular discipline can address the needs of these affected children, the results will be distributed to all the systems that serve these children, and will serve as a basis to:

- Improve the efficiency of the services rendered to children affected by HIV/AIDS;



- Develop new services if necessary, and also to increase the influence of all the professionals in the public service system on the policies relating to children affected by HIV/AIDS.

## **1.17 LAY-OUT OF THE STUDY CHAPTERS**

- **Chapter 1.** Comprises introduction and problem statement
- **Chapter 2.** Outlines the research methodology followed in this study.
- **Chapter 3.** Constitutes data presentation and literature control.
- **Chapter 4.** Deals with discussion of the findings, the conclusion reached as well as recommendations made, and finally, the study limitations.

## **1.18 CONCLUSION**

In this chapter, the introduction and the problem statement are discussed. In the following chapter, the research methodology will be full discussed.

## **CHAPTER 2**

### ***Research methodology***

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#### **2.1 INTRODUCTION**

Given in this chapter will be the complete account of methodology executed in the course of the study process. The research design will be described in order to clarify how the researcher implemented the qualitative research method in eliciting the needs of children affected by HIV/AIDS. The units of analysis, sampling, research technique, and measures used to ensure trustworthiness of the results will be discussed. Finally, the ethical considerations and data analysis will be discussed.

#### **2.2 RESEARCH DESIGN**

The research design is defined as a structural framework, or route planner of the study that maximizes control over factors that could influence the study. It can also be seen as a set of guidelines and instructions to be followed in addressing a research problem (Burns & Grove, 2001:223; Mouton, 1996:107). Based on the purpose of the study, a non-experimental research design of a descriptive, exploratory and contextual nature in the qualitative paradigm was used to explore and describe the needs of children affected by HIV/AIDS.

This design was used because the aim of qualitative research is to understand the human phenomenon of interest (Mayan, 2001:9-10). Need is a human phenomenon that needs to be understood by the people experiencing it. As seen through the eyes of the phenomenologist, a human phenomenon is shaped by the culture, history, purpose and values, and these in return are also influenced by this human phenomenon (Burns & Grove, 2001:65).

### **2.2.1 Qualitative design**

Qualitative design refers to a systematic, interactive and subjective approach used to gain insights into the life experiences through discovering meaning given to them (Burns & Grove, 2001:26). Thus it is suited to identifying, documenting and interpreting fully the meaning people place on events, processes and structures of their lives.

Through qualitative enquiry, people's perceptions, assumptions, judgements, and suppositions become clear and can be placed in context in the social world around them. Thus, the phenomenon is being studied in its particular context and through the perspective of the individual living it (Cormack, 2000:145; Bailey, 1997:39; Wilson, 1993:216-217; Leininger, 1985:5). Qualitative research thus refers to the meanings, concepts, definitions, characteristics, metaphors, symbols, and descriptions of things (Berg, 1995:3).

This study aimed at exploring and describing the needs of children affected by HIV/AIDS, and through the qualitative strategy, insight into their needs can be gained from the children's viewpoint, as individuals who lived the experiences.

Commenting about qualitative research, Burns and Grove (2001:26-27) and Maxwell (1996:17) said the strengths of qualitative research are primarily from: its inductive approach, its focus on specific situations or people, its emphasis on words rather than numbers, and its intention to give meaning to the whole (holistic). The numerical value of the needs of children affected by HIV/AIDS was not going to project an image of their plight, but their words put more emphasis on how being an AIDS pre-orphan or an orphan created a pool for their problems.

As qualitative approach is based on a holistic worldview, it believes in the existence of multiple realities; in creating a meaning and understanding the unique, dynamic, and holistic nature of human beings, which is context bound. Qualitative research is committed to the participants' frame of reference, because what is known about the phenomenon now has a meaning within a given context and changes over time, and also the perceptions are different for each person. For these reasons, the needs described by these children will only be meaningful in their context, and these needs are expected to change over time. This approach considers the researcher as a co-participant in the discovery and understanding the realities (Cormack, 2000:143-144; Burns & Grove, 2001:28; Streubert & Carpenter, 1995:8-10).

### **2.2.2 Descriptive research**

Descriptive research provides an accurate portrayal or account of characteristics of a particular individual, event, or group in a real-life-situation, for the purpose of discovering new meanings (Burns & Grove, 2001:30). As cited by Mouton (1996:102), descriptive studies provide a truthful description of the phenomenon in the world, making claim about how things are, and what the actual state of the affairs is. The focus includes conditions that exist, practices that prevail, beliefs and attitudes that are held. This study was descriptive because it sought to understand the actual state of the children affected by HIV/AIDS, and their uninterrupted descriptions of their real-life situation.

Streubert and Carpenter (1995:36-44) stated that to capture the realities of the participants there must be a link between the <sup>2</sup>*emic* and <sup>3</sup>*etic* view, and for this reason the children affected by HIV/AIDS in Mangaung were allowed to express their views concerning their needs, and this was not simply their portrayal of their needs; it was part of the reality that the researcher was trying to understand, "the *emic* view." Through the transcription and analyses of the

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<sup>2</sup>. *Emic* refers to the local or indigenous interpretation. it is concerned with realities as people perceive them.

data collected from the children affected by HIV/AIDS, the *etic* view was incorporated. The data obtained can thus be used to assess and justify current conditions and practices, or to make room for improvement with regard to the services rendered to children affected by HIV/AIDS.

### **2.2.3 Exploratory studies**

The purpose of exploratory studies is to explore the dimensions of a phenomenon, the manner in which it is manifested and other factors with which it is related (Brink, 1997:10-11). The design is appropriate for areas about which health visiting has little theoretical or factual knowledge, and also in the case of a more persistent phenomenon. HIV/AIDS is a persistent phenomenon, and so its consequences: the pre-orphans and orphans.

As the name suggests, this design investigates and provides more insight or in-depth meaning of life events for a particular group of subjects who share a particular event (Cormack, 2000:217-218; Brink, 1997:11; Neuman, 1997:19-20; Parse, Coyne & Smith, 1985:91; Babbie, 1992:90). The children in this study shared the naming "*orphan and pre-orphan*" and their naming was due to HIV/AIDS.

### **2.2.4 Contextual design**

The aim of a contextual design is to investigate a single individual, or a limited number of individuals or situations, and preserve the individuality of these in the analysis. With this design, phenomena are being studied because of their intrinsic and immediate contextual significance, thus they are able to understand how events, actions, and meanings are shaped by the unique circumstances in which they occur (Maxwell, 1996:17, 19; Mouton, 1996:133; Guba & Lincoln, 1990:45).

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<sup>3</sup> Etic refers to the universal or common explanation of an idea or behaviour as viewed by the researcher or outsider.

The subject matter of qualitative research is social reality. This social reality is not a fixed entity, it changes and develops according to people's experiences and the social context within which they find themselves (Cormack, 2000:143). As Maxwell (1996:17) describes, qualitative research is suited to understanding the particular context within which the participants act, and the influence that the context has on their actions.

Qualitative researchers have an obligation that the natural context of the phenomena must not be disturbed (Streubert & Carpenter, 1995:10-11). Based on this, in-depth interviews were conducted with the children affected by HIV/AIDS within the natural context of their setting "*their homes*", in Mungaung where the plight of HIV/AIDS caught up with them: where they watched as HIV/AIDS ripped apart their sense of hope. The researcher paid three visits to the homes of the subjects prior to interviews, as to minimize the effect of intrusion, and improve the relationships context.

Besides setting and relationship context, the study was contextual in nature, as the phenomenon "needs" was discovered in terms of its immediate contextual significance, the children who experience these needs being HIV/AIDS orphans and the pre-orphans.

### **2.3 UNITS OF ANALYSIS**

Unit of analysis refers to the type of unit the researcher uses when measuring variables. Common units in social research are individuals (Neuman, 1997:113). This is also referred to as population or target population; meaning the elements that meet a certain criterion as to be included in a given universe. For this study the units of analysis were children affected by HIV/AIDS.

### **2.3.1 Sampling**

This is a process of selecting a group of people, events or other elements with which to conduct a study. This subset of the population that is selected for a particular study, from which data will actually be collected, is referred to as sample (Wilson, 1993:172).

Mayan (2001:9-10) and Field and Morse (1990:93-94) indicate that the aim of qualitative sampling is to understand the phenomenon of interest. Thus qualitative researchers are mostly drawn to the following key features when they do sampling:

- Usually, they work with small samples of people nested in the context and studied in-depth. Wilson (1993:172) also stressed that the study becomes feasible and logical when smaller units of the population are studied;
- If small units are drawn, less time and energy are consumed, and the study becomes cost-effective;
- It is easier to control the hawthorn effect and other variables that might have an effect on the study if small units are used;
- Sampling tends not to be random;
- Richness of data gained is based on deep understanding, not on prediction or assumption.

In this study, needs as perceived by children affected by HIV/AIDS was the phenomenon of interest.

### **2.3.2 Sampling criteria**

According to Burns and Grove (2001:366), sampling criteria lists the characteristics essential for membership in the target population. This criterion is developed from the research problem, operational definition and the purpose of the study, the variables and the design. The characteristics of inclusion criteria need to be logically provided; however, care must be taken not to narrow and restrict the sampling criteria as it will reduce the sample size or make it difficult to obtain the sample.

The sample/units of analysis in this study were composed of children in Mangaung whose parent/s was/were ill or dead due to HIV/AIDS. The inclusion criteria into the study were as follows:

- Children were between the age of 11 and 18 years. At this age, their cognitive development allow them to be more aware of their needs, hence it was easy for them to verbalize their needs; as at this age their operational thinking allow them to develop hypotheses about possible outcomes of problems and evaluate these outcomes comparatively (Pawlik & Rosenzweig, 2000:256-257);
- These children were able to speak and understand Sesotho, Xhosa, or Tswana, as these are the main languages that are used in Mangaung and the interviewer is also fluent in them;
- The children were all residents of Mangaung, as the study concerns the children in Mangaung affected by HIV/AIDS;
- The children did express willingness to participate in the study;
- The children were either paternal or maternal orphans or both due to HIV/AIDS, or;



- Either one or both parents of these children were ill due to HIV/AIDS;
- The parents or caregivers of these children gave consent for the children to participate in the study.
- Children 18 years of age, gave consent themselves, as they were heads of households.

### **2.3.3 Sampling technique**

This is the process by which the sources of data were identified and selected for inclusion into the study (Cormack, 2000:155). The method used to select children affected by HIV/AIDS was a non-probability convenience (accidental) sampling method.

Non-probability sampling is mostly used in exploratory studies that are designed to increase the knowledge of the field of study, and are not intended for generalization to large population (Burns & Grove, 2001:374; Cormack, 2000:141). Need is a changeable and/ context-specific phenomenon, and according to Knight (2002:19), the researchers that are investigating phenomena that are context-specific and/or changeable, should not generalize their results; hence, the results of this study will be generalised only to the children in Mangaung who are affected by HIV/AIDS and were interviewed.

A convenience (accidental) sample provides means to acquire information in unexplored areas, but is unacceptable for confirmatory studies. The greatest advantage of convenience sampling is its accessibility. In convenience sampling, subjects are included in the study because they happen to be in the right place at the right time, thus, as also confirmed by Burns and Grove (2001:3740), the researcher in this study included the available subjects that fit the inclusion criteria into the study, until saturation of data was reached.

In this study, the subjects were found through the help of the home-based care workers. These home-based workers from Hospice introduced the researcher to the families that were affected by HIV/AIDS. In these families, the home-based care workers were either looking after the ill parent (in the case of pre-orphans) or looked after the parent before death (in the case of orphans). Through this networking the units of analysis that fit the inclusion criteria were identified in the community, and those that meet the inclusion criteria were recruited to participate in the study.

The researcher opted for a convenience sample in conducting this study in Mangaung, as other sampling methods could have presented some difficulties in recruiting the subjects. This was based on the fact that children affected by HIV/AIDS, just like people infected by HIV, still isolate themselves because of embarrassment and humiliation, while the community neglect them with a connotation of potential harm (Zerwekh, 2000:47-60 ).

#### **2.3.4 Sample size**

The aim in qualitative research is to understand the phenomenon of interest, and not to generalize the findings to the larger population. Qualitative data provide a comprehensive description nested in a real context and can reveal complexity that can have an impact on the phenomenon, and for this reason the number of subjects in such studies is often limited (Bailey, 1997:40; Jacobson, 1994:96; Mayan, 2001:9-10). In qualitative studies the determinant of the sample size is the saturation of data, and this occurs when there is emergence of repeating themes or when no new information is being discovered (Parse *et al.*, 1985:17). In this study, saturation was reached after ten subjects had been interviewed.

## **2.4 MEASURING STRATEGY / RESEARCH TECHNIQUE**

The purpose of a research technique is to select a method by which the researcher can obtain the information of interest. The ideal technique for field research is questioning (Uys & Basson, 1994:55-58). In this study an in-depth interview was used as a method of data collection.

### **2.4.1 Interview**

This is a face to face verbal interchange in which one person – the interviewer – attempts to elicit information or expressions of opinion, attitudes, values, perceptions and experiences from another person or persons towards his/their environment (Burns & Grove, 2001:420; Minichiello, Aroni, Timewell & Alexander, 1992:88; Uys & Basson, 1994:59).

In this study, the interview was used to obtain information about the needs of children in Mangaung who were affected by HIV/AIDS. This method of obtaining information was chosen because the subjects were children who were unlikely to express themselves fully in writing. As Burns and Grove (2001:422) recommend, interviews allow collection of data from subjects whose ability to express themselves is marginal or who are unlikely to complete questionnaires.

Interviewing can take a variety of forms. In this study the researcher conducted in-depth/unstructured interviews with the subjects until saturation of data was reached.

#### **2.4.1.1     *In-depth interview/unstructured interview***

This is a non-directive and non-restrictive type of interview, in which the initiative is almost completely in the hands of the subject. It is a repeated face to face encounter between the interviewer and the subjects. The aim of this method is to reconstruct reality from the world of the participants through exploration and description (Berg, 2001:90-97; Cormack, 2000:20, 293; Mayan, 2001:14-15; Wilson, 1993:224).

The intent of unstructured interview as described by Minichiello *et al.* (1992:59), was to get the meanings attached to the perception of children in Mangaung who were affected by HIV/AIDS, without introducing the researcher's conception of it. This intent blends well with the aim of qualitative research, which is to examine social life by gaining an understanding of the meaning people attach to their experiences and behaviours

In-depth interviewing was the means by which the researcher gained access to, and subsequently understood the private interpretation of the social reality that the individual child affected by HIV/AIDS hold. The aim of the researcher was to understand the meaning attached to the needs of children affected by HIV/AIDS. There was no other methodological strategy that could have been more appropriate than unstructured interviewing to provide a sufficient avenue of inquiry.

#### **2.4.1.2     *Advantages of interview***

According to Burns and Grove (2001:422) and Wilson (1993:224), the interview has a number of important advantages:

- It has a better response rate, as the subjects are invited to tell their story face to face to an empathetic person, rather than mailing an impersonal questionnaire or a structured data form. This was appropriate in this study, as children also being affected by the stigma

associated with HIV/AIDS were interviewed by the person who has had contact with them and had shown empathy during their discussion prior to the interviews;

- It allows a researcher to collect data from people who, either because of their literacy level or some other communication barrier simply cannot write. In this study the subjects were children whose literacy level cannot be compared to that of an adult, and therefore interviewing was the best way to obtain data;
- It is more effective in gaining insight into people's complex feelings or perceptions, because communication skills such as reflection, silence, probing and validation were used to gain more understanding. In this study, interest was shown in the subjects as individuals and also in what they were saying, thus gaining insight into their feelings;
- It allows the researcher to clarify responses that are not fully understood, to probe certain responses in more depth, and to reword and rephrase the question so that they are more easily grasped by the interviewee.
- It allows the researcher to discover the unexpected, hence giving an opportunity for further research.

Unstructured interviews are at the heart of qualitative inquiry, because in most cases the participants make use of their own language to fully and freely describe their experiences. In this study the following languages were used per subject's choice: Sesotho= (3), Tswana= (4) and Xhosa= (3).

### **2.4.1.3      *Disadvantages of interviews***

As with any other method of obtaining data, there are shortcomings and limitations surrounding unstructured interviewing. According to Burns and Grove (2001:422) these interviews:

- Require more time than questionnaires and scale. It took 45 to 55 minutes for each interview to be completed in this study. Though it seemed long, the rich data obtained was more beneficial than a waste of time;
- Interviewing is considered more costly, and to reduce the costs for the study; no translators were used, as the researcher was familiar with the languages used by the children affected by HIV/AIDS;
- Interviewer bias is a major threat to the validity of the findings. In this study, as recommended by Streubert and Carpenter (1995:22), the researcher's thoughts, feelings and perceptions about the phenomenon were bracketed before the beginning of the study and throughout collection and analyses of data in order to increase validity of results. Furthermore, a pilot study was done in order to examine the validity of the research question and the design.

## **2.5      PILOT STUDY**

Cormack (2000:24-25) describes the pilot study as a smaller version of the proposed study, providing a trial run before embarking on the actual study. Seidman (1991:29) defines the "verb pilot" as a guide along strange paths or through dangerous places. As described by Cormack (2000:24-25), the pilot study serves the following purpose:

- It facilitates the testing of, the adequacy of the research design and logistics of the main study, and helps the researcher to identify problems with the study design, which can be rectified before embarking on the actual study;
- It gives the researcher experience of administering the data-collecting instruments to the subjects, thus to test the research question;
- It helps to determine whether the instrument is collecting the type of data required and whether the subjects are able to use those data;
- It provides an opportunity for analysing the research.

As the researcher had no experience in interviewing, it was advised that a fieldworker be use to conduct the interviews, while the researcher would be responsible for taking field notes.

The identified fieldworker had experience with the social and psychological issues that affect children. She is a trained registered nurse, who has psychiatric nursing science as well as a post-basic degree in child psychiatry. This made her an ideal person to deal with children affected by HIV/AIDS.

### **2.5.1 Pilot no.1**

As proposed, this pilot study was performed by the field worker as a trial before embarking on the major study. The fieldworker had to conduct two interviews for the purpose of the pilot study.

Before the fieldworker could conduct the interviews, the researcher twice visited the two homes of children affected by HIV/AIDS, and who had met the inclusion criteria. With the first visit, the home-based care worker introduced the researcher to the families of the subjects to be recruited for the pilot study. During this visit the respondents were informed about the purpose of the study, the audiotape that was used and the field notes as instruments for collecting data. They were also informed about the ethical considerations. When interest was shown, an appointment was made for an interview.

The researcher paid the second visit to the homes of the subjects, the purpose being to build a rapport with the subjects and also to find out if the subjects were still interested in participating in the pilot study. The subjects and the caretakers were also informed about the fieldworker who would be conducting the interview, as the researcher was still inexperienced in conducting the interviews.

On the day of the interview, the fieldworker and the researcher drove together to the homes of children to be interviewed. On two consecutive days, the fieldworker conducted two interviews; one with an HIV/AIDS pre-orphan, and on the second day with an orphan, while the researcher was responsible for taking the field notes during the visits and also during the interviews.

The verbatim transcripts and the field notes were read and evaluated as to whether the desired information had been obtained during the interview, and whether the method and the design were appropriate. After discussing the verbatim transcripts (data collected by the fieldworker) with experts (that is the supervisor and another expert in qualitative research), it was found that there were many leading questions that were irrelevant to the purpose of the study. For this reason, the following were suggested:



- That the researcher must conduct the interviews herself.
- That the fieldworker be used for counselling purposes for children who would be emotionally affected during the process of the main study.
- That it would be advisable to do another pilot study.
- That the researcher must undergo special training in interviewing.

### **2.5.1.1      *Preparation of the researcher as the interviewer***

The quality of the data collected through interviewing depends on the skills of the interviewer. As Berg (1995:56), Minichiello *et al.* (1992:114), Kvale, (1996:147) and Burns and Grove (2001:421) maintain, the researcher does not suddenly becomes a superb interviewer overnight. There is a need for training and practice. Before commencing with the interviews for the pilot study, the researcher had to undergo training in interviewing as suggested.

The researcher read books on interviewing. Besides reading, the researcher also learned how to interview by role-playing with a more experienced interviewer. This experienced interviewer had conducted many interviews with children and people experiencing psychological problems. She is lecturing psychiatric nursing and is currently pursuing Doctoral studies. The role-play was video-recorded, and was later used to evaluate and retrain the researcher for interviewing. Only after this training the researcher was allowed to conduct the interviews; hence the need for the second pilot study.

### **2.5.2 Pilot study no.2**

In this pilot study, the researcher did two home visits in the homes of the respondent who met the inclusion criteria in preparation for the interview. With the first visit, the home-based care worker introduced the researcher to the family of the subject to be recruited for the pilot study. The respondent that was recruited was informed about the purpose of the study and how it would be carried out, as well as the ethical considerations.

The researcher paid a second visit to the home of the subject, this being to build a rapport with the subject and also to find out if the subject was still interested in participating in the pilot study. When interest was shown, an appointment for the interview was made.

The researcher then conducted an interview with one subject. The audio-taped interview was transcribed. The verbatim transcripts as well as the field notes were analysed by the researcher's supervisor and a qualitative research expert. The shortcomings that might affect the major study were identified as:

- (1) Context intrusion. The subject seemed not to speak freely. This prompted the researcher to pay extra visits to the homes of the subjects before doing an interview. These visits would then minimize context intrusion, as the researcher would now be considered one of the family visitors, hence building a relationship. According to Mayan (2001:28), visits enhance reliability of the results, as misinformation, distortion or presented "fronts" are overcome.
- (2) It was identified that the phraseology of the research questions was not clear to the respondents. The questions read thus:

For the pre-orphan child the central question of discussion was:

- **Can you please tell me if there is something in your life in general that is lacking since the illness of your parent/s?**
- **Please tell me more about your needs.**

For the orphan the question read thus:

- **Can you please tell me if there is something in your life in general that is lacking since the death of your parent/s?**
- **Please tell me more about your needs.**

The responses were too brief and limited. The subject seemed not to understand the word "need". According to Burns and Grove (2001:422-423), children view topics differently than adults do, and it is important for the interviewer to use words that children tend to use to define situations and events. The question was phrased and rephrased before it was well understood. It was then modified to read thus:

For the pre-orphan:

- **Will you please tell me more about all the problems that you are encountering since the illness of your mother/father?**

For the orphan:

- **Will you please tell me more about all the problems that you encountered since the death of your mother/father?**

The pilot study further prepared the researcher with interviewing skills; hence, the researcher became alert to elements that could detract from the objective of the study.

## **2.6 THE PROCESS OF DATA COLLECTION**

Data collection is a series of interrelated activities aimed at gathering rich information needed to answer the research question (Creswell, 1994:110).

### **2.6.1 Gaining access**

Interviewing involves a relationship between the interviewer and the participants. How the interviewer gains access to potential participants and make contact with them can affect the relationship and every subsequent step in the interviewing process (Seidman, 1991:31).

Gaining access to the field involves the researcher being given permission to conduct the research (Cormack, 2000:130). In this study, data collection did not commence until the researcher received approval from the:

- Ethics committee of the Faculty of Health Sciences at the University of the Free State (see Annexure B);
- Executive Director of Naledi Hospice (Formerly Bloemfontein Hospice) (see Annexure C).

The home-based care workers from Naledi Hospice introduced the researcher to the families of the subjects that met the sampling criteria. These home-based care workers had a good relationship with the families of the subjects. It was this type of networking that built the initial relationship with the caretakers and later, the subjects.

On the day of the visit, the researcher was wearing a professional uniform, as it was the first encounter with both the caretaker and the ill parent. According to Neuman (1997:354), the presentation of self sends a symbolic message '*a person from a caring profession*'. The home-based care worker introduced the researcher as a nurse researcher who was interested in needs of children whose parents are either ill or dead. The concept, HIV/AIDS was only mentioned to those caretakers and subjects who knew the HIV status of the parents, or to the parents who had their status disclosed.

This first visit was made during school hours while the subjects were still at school, as this was the only time available for the home-based care worker to take the researcher around to the homes. This was later identified as having some benefits in the form of social networking, as the researcher came to know, and was introduced to the subject by the caretaker or the ill parent. According to Wilson (1993:178), social networking is an effective way of soliciting the subjects, and Berg (1995:95) also comments that it is a better way to access the subjects and has greater prospects of gaining further cooperation.

During this first visit, the researcher showed genuine concern for and interest in the family as a whole. These social skills and personal charm were used to build a rapport with the caretaker (Neuman, 1997:355). After establishing trust with the caretaker/parent, an appointment was made to meet with the subject; this would be the second visit to the family.

On the second visit the researcher introduced the study to the subjects. The purpose of the study and the ethical issues were explained to the subjects, and they were allowed to ask questions and request clarifications as needed. After the subjects agreed to participate, an appointment for an interview was made. The appointments that were made for the interviews accommodated the subject's choice of location, date and time. The researcher was also comfortable with the schedule (Seidman, 1991:40).

Prior to the date of the interview, the researcher paid a third visit in order to confirm the scheduled interview appointment, minimize the intrusion and maintain the natural context of the setting (Streubert & Carpenter, 1995:11). This is also recommended by Seidman (1991:41), when reporting that, *'few things are more frustrating in an interview study than to drive few hours to an appointment only to have the participant not show up'*.

### **2.6.2 Conducting the interview**

The interview was conducted in an atmosphere that was quiet, relaxed and free from everyday disruptions, and as Burns and Grove (2001:422) and Hopkinson (1999:206) mentioned, this facilitated free expression of feelings, hence rich data would be gained. In contrast, however, Cormack (2000:29600) indicated that the subjects' homes are not the best places for conducting the interviews, as the interviewee might not be able to maintain a safe place, free from intrusion.

The researcher maintained the advice of Mouton (1996:133), that phenomena in qualitative designs should be studied because of their intrinsic and immediate contextual significance. Taking the affected children from their social setting could have been like stripping the context of interest. The interviews in this study were therefore done at the homes of the subjects, except for two subjects who requested to be interviewed at the clinic. The personnel at the clinic provided a quiet room, and privacy was maintained at all times.

At the homes of the respondents, some form of privacy was provided where the interviews were conducted. A separate room was given and other people in the family were told not to disturb. As Creswell (1994:124) advises, the room was free from distractions and it lent itself to audio-taping of the interview.

Tape-recording is the best way by which the spoken words can be transformed into a written text (Seidman, 1991:87). The interviews were then tape-recorded per subjects' permission. It is believed that the tape recorder inhibits interaction and hence affects the responses of the participants. In this study the researcher used a small unobtrusive tape-recorder to lessen the intimidation. Eye contact was maintained throughout the interview in order to facilitate subjects' participation (Minichiello *et al.*, 1992:134-137).

Besides these shortcomings, Seidman (1991:87) as well as Minichiello *et al.* (1992:135) outlined the following advantages of using a tape-recorder for interviews:

- It preserves the words of the participants, and if something is not clear in the transcript, the researcher can return and check the accuracy, as the original data is available;
- It enhances greater rapport by allowing a more natural conversational style;
- It allows greater analytic depth, because the anecdotal information and the ambiguity of response are still available to the researcher.

The interviews commenced after the caregiver had signed the consent form (see Annexure D). After signing consent, the caregiver was allowed to leave the room where the researcher and the respondents were, before the interview commenced.

The interview started by the researcher greeting the respondents, and as a way of breaking the ice the researcher asked the respondents about their choice of sports, subjects at school, as well as about their homework and whether or not they would need help.

The respondents were allowed to relax and show eagerness to talk before the research question was introduced to them. The interview question was adopted to fit the individual child affected by HIV/AIDS.

For the pre-orphan child the central question of discussion was:

- **Will you please tell me more about all the problems that you are encountering since the illness of your mother/father?**

For the orphan the question read thus:

- **Will you please tell me more about all the problems that you encountered since the death of your mother/father?**

The subjects were given sufficient time to think about and describe their needs freely and extensively in their own words. The researcher permitted the subjects freedom of responses and description, to illustrate how they make sense of their perspective, and how their behaviour was influenced by their views.

This was allowed because the aim of qualitative research is to understand human perspectives from the totality of their life ways, bearing in mind the dynamic interplay of these life ways with the social, economic, political, religious and cultural values within the historical and meaningful life events (Burns & Grove, 2001:65; Leininger, 1985:21-24).

Their answer to the question took the form of a story, a narrative of their views concerning their needs. This was not simply the account of their perspective, but it was that part of reality that the researcher was trying to find the essence of meaning (Cormack, 2000:146; Kvale, 1996:28; Maxwell, 1996:17).



The subjects were motivated to participate spontaneously, and through the use of communication techniques, more information was elicited and interviews were focused around the central question.

### **2.6.3 Communication techniques**

Communication techniques that the researcher used to get more information from the subjects about their needs were:

#### **□ *Listening***

Listening is hearing out loud. It is the common denominator of all the other interviewing techniques and one of the basic keys to understanding (Collins, 1977:71-72). To show the subject that she was listening, the researcher in this study made use of verbal cues like "mmm", "uh", and "head nodding". Listening enables the researcher to understand, and enables the client to bring major facts and feelings to the surface. As Covey (1994:241) commends, listening is a principle in the field of interpersonal relationships. This techniques is quoted thus in the Bible: He who answers a matter before he hears it, it is a folly and a shame unto him (Proverbs, 18:13).

#### **□ *Silence***

Successful interviewing is largely dependent on the interviewer's "will to abstain"-to hold herself back from talking more than is necessary. Besides being absence of communication; silence itself is a specific channel for transmitting and receiving messages. Silence provides meaningful moments of reflection for the interviewee, and gives both the interviewer and the client an opportunity to contemplate thoughtfully what has been said and felt, and to formulate new ideas and gain new perspectives on the matter under discussion (Collins, 1977:69-70). The researcher made use of silence, but it was not prolonged or frequent to hinder the interview. Silence was combined

with eye contact and inquiring glances to elicit more information from the subject.

#### □ ***Reflection***

This is the process whereby the interviewer repeats the same key words as the interviewee, with the purpose of stimulating further elaboration of significant areas that are being vaguely or ambiguously expressed by the interviewee (Hornby, Hall & Hall, 2003:28, 30; Okun, 2002:81; Collins, 1977:79). The researcher communicated to the respondents the understanding of their concerns and perspectives. The researcher reflected on the respondents' feelings as observed, as well as on their meanings.

#### □ ***Probing***

This is a neutral request to clarify an ambiguous answer, to complete an incomplete answer or to obtain a relevant response (Neuman, 1997:257). As cited by Lofland and Lofland (1984:56) in Berg (1995:38-39), the purpose of probes is to obtain the character and contour of narratives or accounts as set by the interviewee in his own terms. The interviewer recognized inaccurate response, or picked up a comment made by the subject, and used probe where needed.

This took the form of non-verbal communication in which the researcher made use of eye contact, tilt of the head, raised eyebrow or unexpected silence; as Burns and Grove (2001:422), Neuman (1997:257) and Berg (1995:38-39) recommended, this took the form of verbal communication, in which reflection and validation were used thus: "I don't think I understand what you mean". However, minimal verbal communication techniques were maintained in order to make the subjects feel less threatened. As advised by Mayan (2001:15), Burns and Grove (2001:422) and Berg (1995:39), where used, it was in a gentle manner so that the researcher would not disturb the subjects

### **2.6.4 Termination of the interviews**

The interviews were ended when the respondents indicated that there was nothing left to be said. This was demonstrated by the respondents' long periods of silence in which the researcher responded by asking the respondents to explain whether their silence meant something, in which case they reported that there was nothing more to say. On that note, the researcher thanked the respondents, and later on, the caregiver. The researcher then left the homes after giving the telephone numbers where she could be contacted if necessary. Where the need for counselling was identified, the respondents were told about the counsellor even though they all reported no need for counselling.<sup>4\*</sup>

## **2.7 FIELD NOTES**

Besides the interviews, the researcher made use of field notes to collect data as a validation of information given by the subjects. When performing qualitative research, a researcher needs a system for remembering observations, and even more importantly, retrieving and analysing these. Field notes of events experienced through watching and listening were jotted down (Wilson, 1993:222; Neuman, 1997:361-366). These were made immediately after the researcher left the scene.

The following are different types of field notes that the researcher used in order to remember the observations made during the interviews. For demographic purposes, field notes were also made during the three visits to the homes of the subjects.

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<sup>4</sup> (A complete transcription of one in-depth interview is given in (Annexure F) all others are available on request.)

### □ ***Observational notes***

Observational notes are a description 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. "The field researcher believes that the core of social life is communicated through the mundane, trivial, everyday minutia"; thus, what people often overlook, the field researcher needs to learn how to notice (Neuman, 1997:361; Wilson, 1993:222).

In this study the researcher took note of the type of housing, the infrastructure, and number of occupants, where subjects lived, as well as the time of death/illness of the parent. The researcher further took note of the non-verbal cues the respondents made during the interviews.

### □ ***Inference notes/Theoretical notes***

Theoretical notes are purposeful attempts to derive meaning from the observational notes, in which one interprets, infers, conjectures and hypothesizes to build an analytical science (Wilson, 1989:435)

This involves a three-step process in which the researcher listens without applying analytical categories; compares what is heard to what was heard at other times and to what others say; and finally, the researcher applies her/his own interpretation to infer or figure out what it means. The researcher listens in order to climb in to the "skin" of the respondents or walk in their shoes. The researcher observed physical actions, and heard words, and then the background cultural knowledge clued from the context was used to make an interpretation. The researcher took note of the respondent's eye contact as well as the reaction exhibited when the diseased parent's name is mentioned.

The observation made without inferences, were transcribed into observational notes as recommended by Neuman (1997:365).

### □ ***Methodological notes***

According to Wilson (1993:222), these are instructions to oneself, critiques of one's tactics and a reminder about methodological approaches that might be fruitful. Neuman (1997:366) refers to these notes as analytical notes, the acts of planning or attempting to give meaning to the field events. In this study the researcher had to remind herself that she was not a counsellor, but a researcher. As emotions were stirred during the interview, the researcher either waited for the subject to gain control, or she would reflect on something different, instead of using the comforting acts of nursing.

### □ ***Personal notes***

These are notes about one's own reaction, reflection and experiences. Fieldwork relies on the investigator's ability to take the role of the others and be introspective. Personal notes serve three functions: they provide an outlet for the researcher and a way to cope with stress; they are a source of data about personal reaction; they give a researcher a way to evaluate observation or inference notes when the notes are later reread (Neuman, 1997:366; Wilson, 1992:223). The researcher made notes on her fatigue, emotions as well as physical discomfort.

The field notes were made immediately after each visit and interview. This was to minimize the period between data collection and data storing, and to reflect on the data before commencing the next visit or interview. To minimize on the generative process of the interview, the researcher avoided interpretation or analysis of field notes during the visits and interview; however, after finishing with each subject's visits and interview, the notes were interpreted and analysed.

The accuracy and reliability of the findings were also ensured, and as Brink (1997:124) specifies, validity in qualitative research is concerned with trustworthiness of the results.

## **2.8 MEASURES TO ENSURE TRUSTWORTHINESS OF THE RESULTS**

Trustworthiness is a method of establishing or ensuring rigor in qualitative research (Krefting, 1991:215; Lincoln & Guba, 1985:290). The goal of rigor in qualitative research is to accurately represent what those who have been studied experience. As described by Streubert and Carpenter (1995:25-26), the researcher ensured this by demonstrating full attention to the discovered information and by confirming with the respondents the information discovered. The criteria as presented in Guba's model of ensuring trustworthiness as cited by Krefting (1991:214-222) was also used. This model addresses four criteria for assessing trustworthiness in qualitative research:

### **2.8.1 True-value/credibility**

Credibility asks whether the researcher has established the truth of the findings, as viewed through the eyes of those being observed/interviewed, and within the context in which the research was carried out. This criterion asks how confident the researcher is with the truth about the needs of children in Mangaung who were affected by HIV/AIDS, based on the research design, informants and context (Krefting, 1991:215; Lincoln & Guba, 1985:290). This value was achieved through the following:

#### **□ Prolonged engagement**

The intention of prolonging, is to overcome the effects of misinformation, distortion or presented fronts and to establish the rapport and build the trust necessary to uncover what is really going on (Mayan, 2001:28). According to Lincoln and Guba (1985:303), building of trust ensures that pledges of confidentiality will be honoured, that there are no hidden agendas and that the

interests of the subjects as well as their input and influences into the inquiry process will be honoured.

The researcher in this study paid three visits to the homes of the subjects, where the researcher assumed the role of a professional nurse as well as a researcher, as she was wearing the professional uniform during the first visit. By assuming the role of a nurse, the caretaker or parent felt at liberty to discuss things like self-medication, self-care and health talks. This was done to eliminate wrong assumptions, understand how they talk and also to show that the researcher valued their views and is interested in their problems.

During these visits, they were afforded an opportunity to ask questions and request clarifications with regard to the study where needed. The researcher also being from the same cultural background as the subjects gave an added advantage, as this made them feel free to ask or to talk about anything.

Later on the researcher felt that the families had accepted her, and she spent 40 to 45 minutes with the respondents during the interview where the respondents were allowed to describe their needs in their language and some of the words and non-verbal cues the researcher used were adopted from the respondents.

#### □ ***Persistent observation***

The researcher, as advised by Lincoln and Guba (1985:304), identified and focussed in detail on those characteristics and elements in the situation that were relevant to the needs of children affected by HI/AIDS.

The researcher took into consideration the non-verbal communication cues of the respondents, as well as other elements in the conversational context, such as silence and continuous repetition of words. Being from the same cultural background, as well as awareness of interpersonal skills complemented this persistent observation.

#### □ ***Member checking***

This is the process of obtaining feedback from the participants to ensure that the researcher heard their story correctly (Patton, 1999:4). In this study a tape-recorded cassette was played back to each respondent for verification and clarification concerning their needs as children affected by HIV/AIDS. Only one respondent in this study requested that the cassette not be replayed.

The copy of the research report was given to two respondents (one pre-orphan and one orphan) to confirm if this was how they perceived their needs as children affected by HIV/AIDS.

#### □ ***Peer debriefing***

It is a process of exposing oneself to a peer for the purpose of inquiry, which might be implicit within the inquirer's mind. This process should engage another researcher in an extended and extensive discussion of one's findings, conclusions and tentative analyses. The task of the debriefer is also to ask questions about the researcher's values, conjectures and decision, and suggesting possible future steps (Mayan, 2001:28). In this study the researcher made use of an independent coder who has a Master's degree, and is also a qualitative research expert, to serve as peer debriefer. The researcher's supervisor, who has a Ph.D. in nursing and is also experienced in qualitative research, also served as a debriefer.



## □ **Triangulation**

According to Burns and Grove (2001:239), triangulation is the combined use of two or more theories, methods, data sources, investigators or analyses methods in the study of the same phenomenon. Patton (1999:3) said, because each method reveals different aspects of empirical reality, multiple methods of data collections and analysis provide more grist for the research mill. In this study the following types of triangulation were used.

- **Data triangulation:** involves the collection of data from multiple sources for the same study. The researcher interviewed ten children and obtained their views concerning their needs. These children were of different age groups and sex. HIV/AIDS had also affected them in diverse ways: some of them were the head of a household; some had lost their parents, while others had ill parents to look after. Data triangulation means comparing and cross-checking the consistency of information derived at different times and by different means, with the intent of obtaining diverse views of the phenomenon under study for the purpose of validation (Burns & Grove, 2001:239; Patton, 1999:5)
- **Analytical triangulation:** involves the use of multiple analysts. A common approach to analytical triangulation is to have those who were studied review the findings. Researchers can learn a great deal about accuracy, fairness, and validity of their data by having people described in that data analysis react to what is described (Patton, 1999:6). In this study, the tape-recorded cassette was played back for the respondents to verify and give clarity on their responses, and at the final stage, the copy of the research report was given to two subjects to confirm whether what the researcher said was a true reflection of their needs. An independent coder, experienced in qualitative research, was also used in the process of analysis in which categories and themes were identified from the verbatim transcripts.

## **2.8.2 Applicability/transferability**

Transferability refers to the degree to which the findings of a particular inquiry can be applied to other contexts or with other subjects (Brink, 1997:124; Krefting, 1991:216; Lincoln & Guba, 1985:290). The aim of qualitative research is to understand the phenomenon of interest, and not generalize the findings to the larger population from which the sample was taken (Mayan, 2001:9). However, the following ensured this criteria of transferability:

### **□ Sample selection**

Sample selection concerns, selection of individuals and context from which a great deal can be learned about the phenomenon (Mayan, 2001:10; Lincoln & Guba, 1985:316). A convenience sample was used where children who are affected by HIV/AIDS were selected for interviewing.

### **□ Dense description**

Dense description concerns the complete and thorough description of methodology presented in this study. This is to provide information as to how repeatable and audible this study might be (Krefting, 1991:220).

## **2.8.3 Consistency/dependability**

Consistency refers to whether the findings of an inquiry would be consistent if the inquiry were to be replicated with the same subjects in a similar context (Krefting, 1991:216; Streubert & Carpenter, 1995:26). The following strategies as outlined by Krefting (1991:221) were used to ensure dependability criteria:

The exact methods of data collection, analysis and interpretation of data have been thoroughly explained in this study. This dense description of the method provides information as to how repeatable and audible the study might be.

The researcher used her supervisor who has experience in qualitative research to check the research plan and the implementation of the plan. During the analysis stage the researcher used an independent coder who is experienced in qualitative research. The researcher and an independent coder compared and discussed their categories and themes, and they reached consensus on the data.

Streubert and Carpenter (1995:26) stressed that *"there can be no dependability without credibility"*.

#### **2.8.4 Neutrality/confirmability**

Confirmability refers to the guarantees that the findings, conclusions and the recommendations are supported by the data, and that there is internal agreement between the researcher's interpretations and the actual evidence (Brink, 1997:125). The findings must solely be the functions of the subject, not of the biases, motivations, or perspectives of the researcher (Krefting, 1991:217). The researcher used the following strategies to ensure this criterion:

##### **□ Bracketing**

This is a mental exercise in which the researcher identifies and suspends or lays aside ideas of what is already known about the phenomenon under investigation. Bracketing is an important aspect when a researcher is uncovering a phenomenon of which he/she knows a great deal, as she may impose on the client instead of allowing the client to fully express his reality (Leininger, 1995:89; Streubert & Carpenter, 1995:313).

The ideas known about children affected by HIV/AIDS were bracketed, and again the researcher retained a neutral stance during the interviews. Knowledge about the possible needs of children affected by HIV/AIDS were not imposed on these children interviewed, but they were allowed to express the reality of their experiences; hence, leading and direct question were not asked throughout the process of the interview.

#### □ ***Intuition principles***

This is an accurate interpretation of what is meant in the description of the phenomenon under investigation (Streubert & Carpenter, 1995:32). It is the process of coming to know the phenomenon, of grasping the ideal as described by the subject. In this study the researcher reflected and weighed the essence of needs of children affected by HIV/AIDS in order to reach a common understanding with the subjects (Leininger, 1985:90; Parse *et al.*, 1985:19-20).

According to Cormack (2000:214), Streubert and Carpenter (1995:32), Maxwell (1996:17), Jacobson (1994:96) and Mouton (1996:102), the descriptions must be as free as possible from unexamined presuppositions. *"Protection against bias is an important consideration"*. For this reason, principles of bracketing and intuition were used during data collection and data analysis, in an attempt to control judgement that may be based on values, motivations and preconception.

## □ **Reflexivity**

Reflexivity refers to the assessment of the influence of the investigator's own background, perception and interest in the qualitative research process. Qualitative approach is reflexive in that the researcher is a participant, not an observer; hence, she cannot be separated from the research (Krefting, 1991:218). In this study the researcher made use of personal field notes to reflect on her own feelings, and these were used during data analysis; therefore her feelings had little or no influence on the results.

Brink (1997:125) believes that if the other three criteria of reliability are achieved, so would the confirmability criterion.

## **2.9 DATA ANALYSIS**

Data analysis refers to a process that involves an effort to formally identify themes and to construct hypotheses (ideas) as they are suggested by data and an attempt to demonstrate support for those themes and hypotheses (Tesch, 1990:113). Bailey (1997:137) and Minichiello *et al.* (1992:285) describe qualitative data analysis as a process of systematically organizing the interview transcripts and the field notes until they are understood in such a way that the research question is addressed.

In this study the researcher did not analyse data simultaneously with the data collection, as Creswell (1994:153) recommended. Instead, the researcher took Siedman's (1991:86) advice of waiting until the interviews were completed before commencing with the data analysis. This was to avoid imposing on the generative process of the interviews. However, the researcher became familiar with the phenomenon under study by dwelling on or becoming immersed in the data during the transcription of the interviews. As Bailey (1997:158) and Streubert and Carpenter (1995:45-46) advised, this immersion in the data helped with the development of tentative concepts to be used for coding.

Before data analysis the researcher clarified the notions, previous knowledge and personal beliefs about the needs of children affected by HIV/AIDS. This process of bracketing as described by Burns and Grove (2001:791) and Leininger (1995:89), enabled the researcher to obtain pure description of the subjects without confirming the researcher's preconceived beliefs. Streubert and Carpenter (1995:33) describe bracketing as phenomenological reduction, in which the researcher isolates what is already known about a particular phenomenon from the pure and real phenomenon.

After the process of bracketing, the audio-taped interviews were repeatedly listened to, and compared with the verbatim transcripts, as they were also read and reread. This comparing was to verify the accuracy of the transcriptions, and as Field and Morse (1990:99) recommend, it was also done to note changes in the voice or tone, significant pause and inflections indicating a highly important topic. In this manner the researcher became immersed in the data. This process of becoming immersed in the data or dwelling on the data helped the researcher to achieve comprehension of data.

During the whole process of data analysis the researcher followed Tesch's (1990) method of data analysis as cited by Creswell (1994:154-155). This method involves eight steps which the researcher followed in a systematic process of data analysis:

- (1) By reading through all the transcripts, the researcher comprehended the data and got a sense of the whole. This step provided the researcher with the necessary background information. As the ideas were coming to mind, they were written down;

- (2) Then the researcher took one interesting interview transcript and read through it. As the researcher read through it, she asked herself what the interview was all about. Attention was paid to the underlying meaning (to what it was saying) rather than the content. As there was transition or switches from one topic to another, distinction was made between content and topic. The researcher then identified topics, and these were written in the margin of the document.
- (3) The researcher read through all the other interviews. Like the first one, attention was paid to the underlying meaning (to what it was saying) rather than the content. As the topics emerged, they were written in the margin. When this was completed, a list of all the identified topics was made. All topics were placed in columns on one sheet of paper: one column per each data document. A comparison was made between all topics. Then, using different highlighters, a connection was made between similar topics. Similar topics (those with the same colour) were clustered together, and this was arranged as major topics. Then the best fitting name that captured the substance was chosen for the clustered topics. This was where the *etic* view as identified by Leininger (1985:238) was co-operated into *emic* view. Another column was made for unique topics that were observed to be important to the research topic, even though their occurrence in the data was rare. The other column was also made for the topics that were considered leftovers.
- (4) At this stage, the researcher arrived at interpretational analysis in which codes were to be written next to the appropriate segment of the text. At this juncture, the clustered major topics as well as the unique topics were abbreviated as codes. As the researcher went back to the data, the codes were written next to the appropriate segment of the text. This process showed how well the topic descriptions corresponded with what was found in the data. It also led to the discovery of new topics that were not previously identified.

- (5) At this stage the researcher was ready for refinement of the organized data; the most descriptive wording for the topics was found and the topics were then turned into categories. To reduce the total list of categories, relations were found between the topics, and lines were drawn between categories to show interrelationship.
- (6) A final decision was then made on the abbreviated category name, and each code was alphabetized. Subsequently a coding<sup>5</sup> session was done. Some segments in the content were too rich to fit in just one category, and these were placed in different categories.
- (7) When coding was completed, the data materials belonging to each category were checked in the context and were all assembled in one place. Each category was done at this time. As the content for each category was identified and summarized, the commonalities, uniqueness, confusions and contradictions, as well as the missing information with regard to the research topic were then identified. This led to some of the data being discarded, as it was not relevant.
- (8) The last step of recoding was skipped, as there was no need for that, the categories being homogenous.

As Reis and Judd (2000:292) advised, categories for coding systems were developed inductively from the insight gained from the interviews, as the theoretical ones could have conveyed the views of the researcher and not the perspective of the affected children.

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<sup>5</sup> Coding is a way of organizing the raw data into conceptualised categories and creates themes and concepts to be used in data analysis (Burns & Grove, 2001:597-598; Neuman, 1997:421).



The researcher used open coding as recommended by Neuman (1997:422), in which each word, line or paragraph was examined and coded in order to discover the subjects' meaning. As Polit and Hungler (1995:522) recommended, the researcher located themes that were then assigned codes in an attempt to convert data to a smaller, more manageable and more manipulative units that can be easily retrieved

The researcher gave an independent coder who is experienced in qualitative research, (she has a master's degree in nursing and qualitative research is her speciality) the raw data of the verbatim transcripts of the interviews and field notes and the protocol with guidelines for data analysis as described by Tesch (1990) in Creswell (1994:154-155). After a period of four weeks, the independent coder and the researcher met to reach consensus on their findings. Then the refinement of themes, groups and categories was done after joint consensus was reached.

Counting of the codes to develop a frequency table was done only to present the needs of children affected by HIV/AIDS from the highest to the lowest frequencies, and should not be interpreted as in survey studies (Polit & Hungler, 1991:505).

The categories and the themes identified with the data are discussed in the next chapter.

## **2.10 ETHICAL MEASURES**

Ethics is the term used to denote the system or code of morals applied during the research process, be it as individual and/or member of a profession. It involves the consideration of moral obligation that one ought to conform to (Mnichiello *et al.*, 1992:230-231; Babbie, 1992:464). Conducting research ethically starts with the identification of the study topic and continues through to publication of the study (Burns & Grove, 2001:191), therefore the following concerns in this study were addressed:

### **2.10.1 The quality of the research**

The performing of nursing research requires expertise and diligence, as well as honesty and integrity (Cormack, 2000:52-53; Burns & Grove, 1997:195; The South African Society for Nursing Researchers, 1996:74). The researcher undertook the study with both personal and professional integrity.

The proposal for this study was first seen and evaluated by the expert committee and the postgraduate evaluation committee as a quality assurance measure. The researcher was also under the guidance of the supervisor who is experienced in qualitative research and has a Ph.D. degree in nursing. At all levels, the researcher attempted to be aware of her personal prejudices and values, which might have had an influence on the study (Uys & Basson, 1991:97).

The researcher did an Advanced Diploma in Clinical Nursing (Advanced Midwifery and Neonatology). A course in interpersonal skills as well as anthropology being the components of this clinical nursing specialist course were also done. The researcher also did psychology and sociology as major subjects in the basic degree program, and these prepared the researcher to deal with people as social and psychological beings. The researcher was then equipped with skills to relate easily to people of diverse origins. Furthermore, the researcher had to do research methodology as a formal preparation for the study.

### **2.10.2 Access through the formal gatekeepers**

Gatekeepers are those individuals or institutions in an organization that have the power to withhold access to the people or situations for the purpose of research (Cormack, 2000:129-134; Minichiello *et al.*, 1992:203-204; Seidman, 1991:30).

In this study the researcher obtained written consent from:

- The Ethics Committee of the Faculty of Health Sciences of the University of the Free State.
- Executive Director of Naledi Hospice (Formerly Bloemfontein Hospice), as this is the institution providing a service to the terminally ill patient through home-based care.
- The caretaker/parent, as the subjects were children.

### **2.10.3 Informed consent**

*Informing* is the transmission of essential ideas and content from the investigator to the prospective participant. *Consent* is the prospective participant's agreement to participate in a study as a subject, which is reached after assimilation of essential information. This phenomenon of informed consent is defined in the Nuremberg code, which states that the voluntary consent of human subjects is absolutely essential (Burns & Grove, 2001:206; Wilson, 1993:247-248). To ensure informed consent, the following were addressed:

#### **□ *Right to know***

The subjects were informed about the following aspects as described by: Wilson (1993:251-252):

- The purpose and the nature as discussed in chapter one;
- The duration of the study and the processes by which the data would be collected, and these were expressed in straightforward lay terminology;

- The ultimate use of the research findings and any personal or social benefits that could derive from the research;
- All the inconveniences, potential harm, or discomforts that might be expected during the interviews, including follow-up interviews that might follow if necessary;
- The right to refuse to participate in the study and the right to withdraw at any time;
- The identity of the researcher and how to contact her were also given.

The Caretakers signed the consent form on behalf of the children who participated in the study, after everything about the study was explained to both the caretakers and the subjects (see Annexure D for a copy of consent form).

#### **2.10.4 Confidentiality**

Confidentiality means that information may have names attached to it, but the researcher holds it in confidence or conceals it from the public. (Neuman, 1997:452-453). In this study the raw data was only accessible to the researcher, the study supervisor and the independent coder. There were no names used in the tapes and the transcribed data, instead numbers and whether the child was an orphan or pre-orphan were used. As Leininger (1985:296) advised, the respondents in this study were made anonymous in the public records and accounts of the research, as all the interview materials were labelled by numbers and whether the respondents were orphan or pre-orphan. The interview materials were also not accessible to unauthorised persons.

### **2.10.5 Right to privacy**

Privacy enables a person to behave and think without interference, or the possibility that the private behaviour or thoughts may be used to embarrass or demean the person later (Wilson, 1993:253). The subjects and the caretakers in this study were aware of the information elicited, and the use thereof, and they gave consent to participate in the study voluntarily. The subjects voluntarily shared their personal views, and with their permission this was used as a source for the research data (Wilson, 1993:253; Babbie, 1992:470-471; Burns & Grove, 2001:200).

### **2.10.6 Protection from harm and discomfort**

Participation of subjects in an interview has risks such as physical discomfort like fatigue, or emotional risks like anxiety. Since these risks usually cease with termination of the study, such studies are described as having minimal risks (Burns & Grove, 2001:203-204; Neuman, 1997:447).

In this study, emotions were stirred during the interviews, especially when the subjects were relating about their deceased parent/s. The researcher suggested the referral of the subjects to the child psychiatry nurse specialist for counselling at the researcher's expense. However, the subjects declined the offer, and in such cases the researcher left her telephone number and asked them to contact her whenever they feel like it.

## **2.11 CONCLUSION**

The research design and method have been discussed in depth in this chapter, in which qualitative, exploratory, descriptive and contextual designs were used. In-depth/unstructured interviews were used to collect data from children affected by HIV/AIDS who met sampling criteria. The ethical consideration and measures to ensure reliability that were followed were also discussed. In the next chapter the data analysis as well as data interpretation will be discussed.

## **CHAPTER 3**

### ***Data presentation and literature control***

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#### **3.1 INTRODUCTION**

The research design and the method followed in this study were discussed in the previous chapter. In this chapter, interpretation of data and literature control will be discussed. The discussion will be based on the needs of children in Mangaung who are affected by HIV/AIDS. The literature control will be conducted for making comparisons as an analytic tool to foster conceptualization (Strauss & Corbin, 1998:53).

#### **3.2 DESCRIPTION OF THE SAMPLE**

The sample in this study comprised ten subjects from Mangaung. All the subjects were affected by HIV/AIDS, either as orphans or pre-orphans. They were of different age, sex and cultural background (see Table 3.1).

As illustrated in Table 3.1, the respondents' ages ranged from 11 to 15 years (50%) and 16-18 years (50%). The ethnicity of the sample was 30% Xhosa, 40% Tswana and 30% Sotho. Almost more than half (60%) were male respondents while 40% were females. The subjects were affected in various ways by HIV/AIDS: pre-orphans were 4 (40%) while the orphans were 6 (60%). The number of years of their experience, either as pre-orphans or orphans ranged thus: As from 1999-2000, there were 60% of the subjects while the remaining 40% had been affected by HIV/AIDS since 2001-2002.

**TABLE 3.1: Demographic information of the sample (N=10)**

CRITETION	CHARACTERISTIC	FREQUENCY
Age	- 11-15 years	5
	- 16-18 years	5
Ethnicity	- Xhosa	3
	- Tswana	4
	- Sotho	3
Gender	- Male	6
	- Female	4
Various ways of being affected	- Pre-orphans	4
	- Orphans	6
Years of (experience) being affected	- 1999-2000	6
	- 2001-2002	4

### 3.3 DATA ANALYSIS

Data analysis refers to a process that entails an effort to formally identify themes and to construct hypotheses (ideas) as they are suggested by data, and an attempt to demonstrate support for those themes and hypotheses (Tesch, 1990:113). Bailey (1997:137) and Minichiello *et al.* (1992:285) describe qualitative data analysis as a process of systematically organizing the interview transcripts and the field notes until they are understood, in such a way that the research question is addressed.

The researcher commenced the analysis by repeatedly listening to the audio-taped interviews, reading and re-reading the verbatim transcripts. Then a certain pattern of concepts was identified and grouped into categories that were used as framework for content analysis<sup>6</sup>.

The independent coder was given copies of verbatim transcripts, field notes and protocol for data analysis. Thereafter a meeting was held to discuss and reach consensus on the categories, sub-categories and themes identified in the transcripts.

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<sup>6</sup> See Chapter 2 for a complete description of data analysis.



Data from the verbatim transcripts were grouped into four main categories and sub-categories. Comprehensive themes were developed to support the sub-categories (see Figures 3.1 to 3.4). The sub-categories were developed strictly from the transcripts, as those that could have been developed from theory, could not have portrayed and conveyed the needs of children in Mangaung who were affected by HIV/AIDS. The main categories identified were:

- Physical needs
- Economic needs
- Psychosocial needs
- Control needs

Under each category, sub-categories were identified and these are reflected in Figures 3.1 to 3.4 as illustrated.

### 3.4 FRAMEWORK FOR DATA ANALYSIS

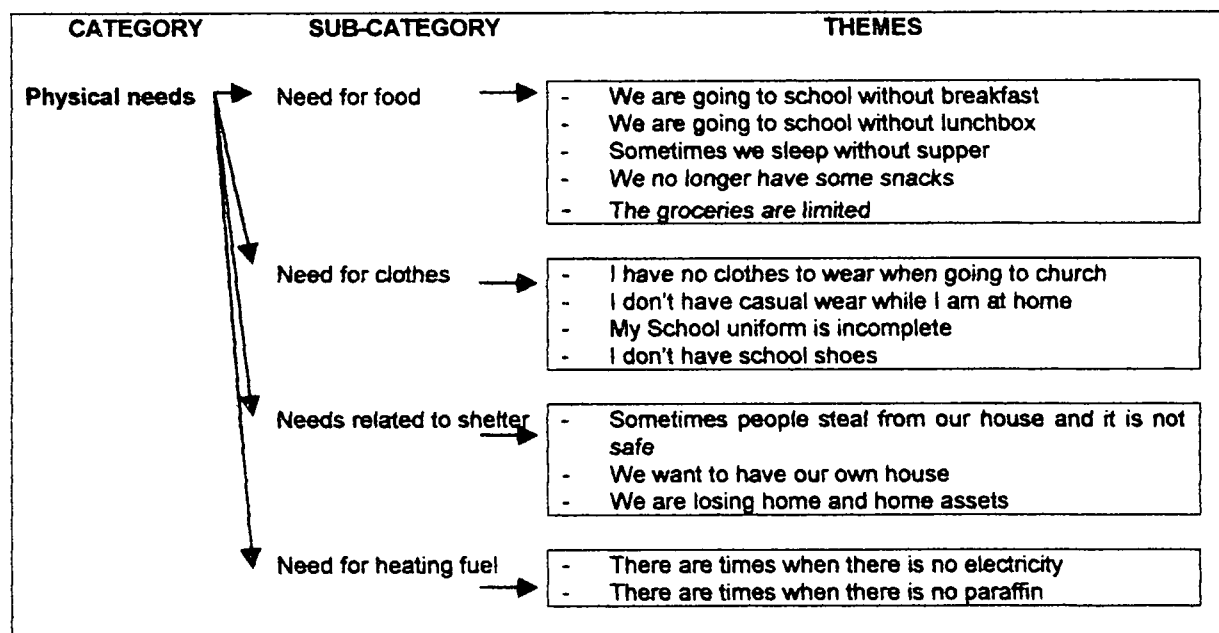
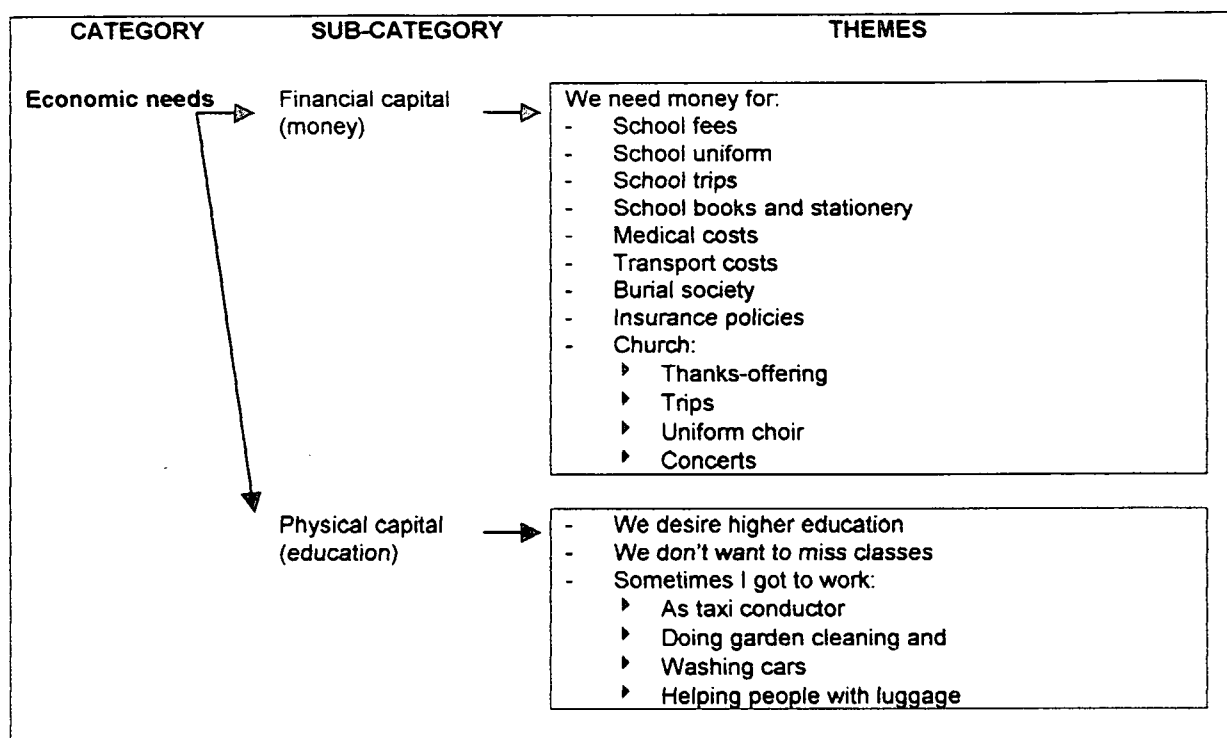
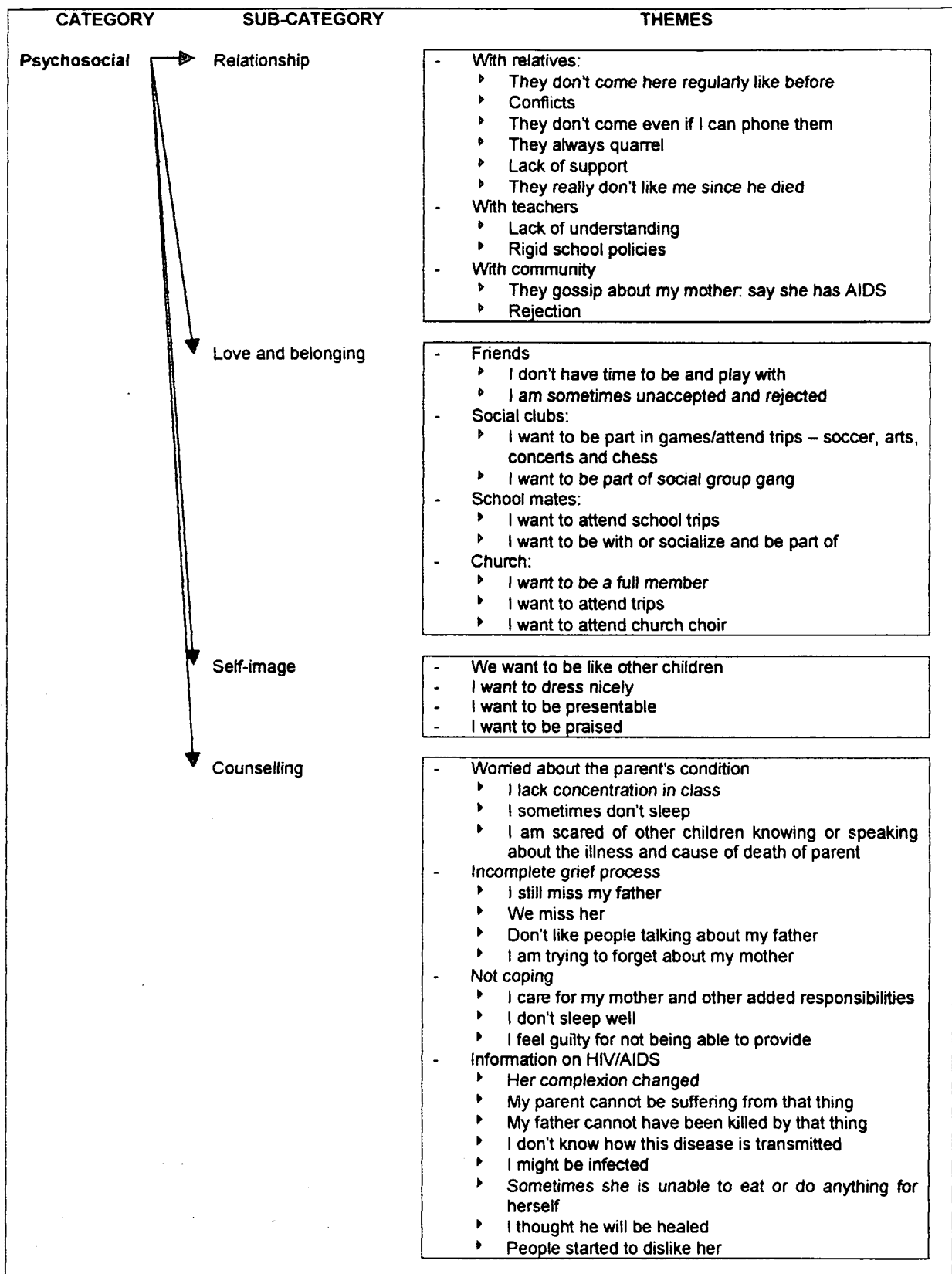


FIGURE 3.1: Physical needs



**FIGURE 3.2: Economic needs**



**FIGURE 3.3: Psychosocial needs**

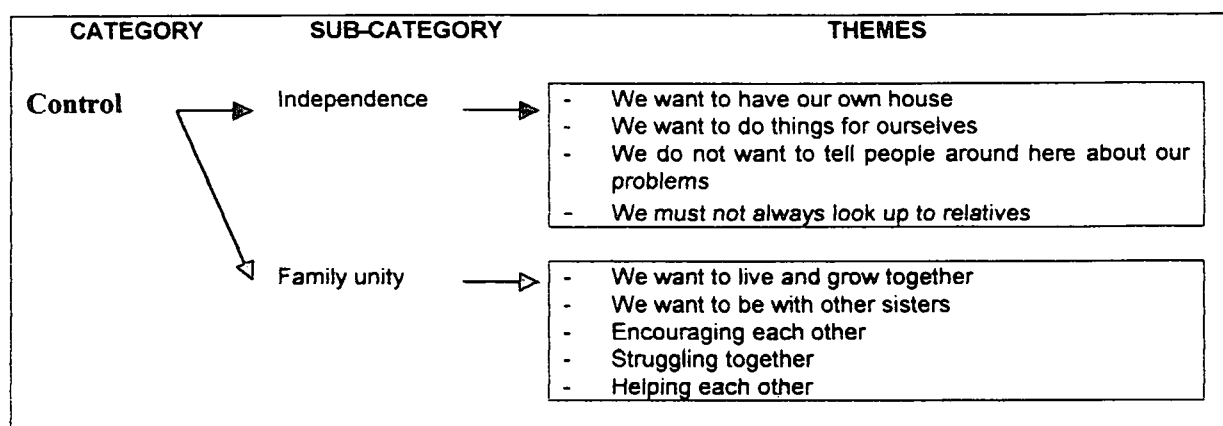


FIGURE 3.4: Control needs

## 3.5 FINDINGS AND LITERATURE CONTROL

### 3.5.1 Needs

A need is some state of affairs which, if present would improve the well-being of an organism. This may be something basic and biological or it may involve social and personal factors and derives from complex forms of learning (Reber, 1995:484). According to the description made by Baldwin (1998:44), a need refers to everything from basic bodily needs such as nutrition and warmth to emotional needs, and these exist within a general social context in which certain needs are culturally or temporarily deemed more important than others.

The respondents expressed various needs during the interviews, and these are represented in Figures 3.1 to 3.4. These needs are also presented in order of their frequency in Tables 3.2 to 3.5.

**N.B.:**

The frequency tables are given only to illustrate how important certain needs were to the respondents. It should therefore not be seen or interpreted as in quantitative designs, because of imprecision in the sampling of the subjects and enumeration of the themes (Polit & Hungler, 1991:505).

**TABLE 3.2: Frequency of the responses (How many times a need was mentioned during the interviews) (N=10)**

NEEDS	FREQUENCY OF RESPONSES
<b>Physical needs</b>	
Food	34
Clothes	33
Shelter	8
Fuel	1
<b>Total</b>	<b>76</b>
<b>Economic needs</b>	
Financial capital	36
Physical capital	25
<b>Total</b>	<b>61</b>
<b>Psychosocial needs</b>	
Relationships	39
Love and belonging	28
Self-image	24
Information	23
Counselling	26
<b>Total</b>	<b>140</b>
<b>Control needs</b>	
Independence	9
Family unity	10
<b>Total</b>	<b>19</b>

### 3.6 PHYSICAL NEEDS

Physical needs involve all the physical processes of a human being, for example breathing, elimination, eating, housing activity, rest, sleep, hygiene and health (Uys & Middleton, 1997:32). While Thomas (2000:104-105), Baldwin (1998:84) and Louw and Edwards (2000:502) describe physical needs as those needs that when met ensures the survival and self-preservation of the individual, and these include the need for food, drink, warmth, harm avoidance and comprehension of the environment. The respondent in this research also emphasized these needs by mentioning them repeatedly as illustrated by 76 responses (see Table 3.2).

The physical needs as expressed by the respondents are also illustrated in Table 3.3. The physical needs have been quantified on the basis of the number of respondents who made reference to the same themes and in the same categories.

**TABLE 3.3: Physical needs of children affected by HIV/AIDS in order of their frequency (N=10)**

NEEDS	FREQUENCY (F)
Need for food:	
❖ Supper	9
❖ Breakfast	8
❖ Lunch box	7
❖ Snacks	2
Need for clothes:	
❖ Smart wear	10
❖ School uniform	9
❖ Church choir uniform	5
❖ Shoes	4
Needs related to shelter:	
❖ Loss of home assets	2
❖ Safe shelter	1
❖ Own home	1
Need for heating fuel:	
❖ Electricity	1
❖ Paraffin	1

The sub-categories of these physical needs will be discussed and their themes as described by the respondents will be given as direct quotes.

### 3.6.1 The need for food

Food is a substance consisting of various nutrients needed for growth and health. It provides fuel, builds tissues, regulates and protects the individual, and is also one of the basic biological needs (Serfontein, 2001:60; Uys & Mulder, 1993:74).

The need for food was evident from most of the respondents. Eight respondents reported that they go to school without breakfast, while seven go to school without lunchboxes (see Table 3.2).

*"There are times that I go to school without breakfast..."*

*"We don't take lunchboxes to school. I really don't mind if I am without food at school, but I feel bad if my younger brothers have nothing to eat at school."*

*"Sometimes I do come home at break time to come and eat, but in most cases there is nothing to eat, and I always go back to school."*

Other studies have indicated that access to food for both HIV/AIDS pre-orphans and orphans is very limited (Gilborn, Jagwe-Wadda, Kabumbuli & Nyonyintomo 2001:19; Richter, 2001:32) and for this reason breakfast and lunchboxes could have been a problem just like the respondents in this study.

All three traditional meals are very important for supplying people with the daily levels of essential nutrients, but studies have shown that breakfast is the most important meal of the day (Robertson, 1998:1; Peaslee & Streeter, 2003:1-3). Breakfast leads to improved strength and endurance in the late morning, as it provides the brain with energy. Much evidence has pointed to the improvement in memory and learning if breakfast has been taken. Vangsness (2003:1-3) too says, if a balanced breakfast is taken, it has benefits for the schoolchildren and teens, as they will score high on tests, have a more positive attitude and have energy and healthier body weights

Despite the reported importance of this first meal of the day, the circumstances made it impossible for the respondents in this study to take breakfast, hence they reported lack of concentration, low scores during the tests, weakness and inability to listen during the class period, as they sometimes go to school without meals:

*"Sometimes we go to school without eating breakfast, and if I didn't have food, I feel weak. And while I am at school, I don't concentrate if I am hungry."*

*"It becomes difficult for me to listen if I had nothing to eat, and if we have to write something like a class test, I would get things wrong because I didn't listen."*

These children's descriptions are in accordance with Serfontein's (2001:60) comments, that food is necessary and critical for mental and physical development. The individual normally develops mental symptoms such as insomnia, fatigue and inability to concentrate, well in advance of the physical signs like anaemia, if nutrients are deprived. This is related to the imbalance of neurotransmitters in the brain, as these transmitters are produced by the amino acids and vitamins acquired from food.

This phenomenon was also identified by Abidoye (2000:609-620), in which the overnight and morning fast among school children was demonstrated to affect memory function and cognition adversely. Spurr (1990:255-166) also comments that undernourished children cannot cope with situations of increased activity, as reduced active tissue is related to decrease in basal metabolic rate, as well as reduced resting metabolic rate, and finally there will be a decrease in the energy available for physical activity.

Nine of the respondents further reported that they sometimes sleep without meals, as there were no other means of getting the food. The respondents in this study were not specific about the types of food they need. They seemed to want anything that could appease the hunger sensation:

*"Most of the time there is no food in the house, because my mother is always without money."*

*"There are times where you will find that there is no money; there is no mealie-meal for porridge..."*

*"There are times when we sleep without food and mother would cry. But I am always comforting her saying God is watching over us..."*

*"There are times that we sleep without food ...."*



Sadly, the findings in this study correlate with what Gilborn *et al.* (2001:19) reported, namely that access to food by orphans as compared to children whose parents are living with HIV/AIDS was very similar, as both groups in their study reported that there were days when they were without food.

Richter (2001:32) also identified that in families where the breadwinner suffers from or has died from AIDS, food consumption drops by 41% while income falls by 52.67% as a result of expenditures on health care and debt incurred for funeral costs. This was explained thus by one respondent:

*"You will find that there are times that there is no food. My mother no longer buys a lot of groceries like before. She is getting sick grants but when those grants do come, we have to pay the money that we borrowed for her to hire the car and see a doctor as she is now and then changing condition."*

Maslow (1970) in Meyer, Moore and Viljoen (1997:440), has indicated that the need for food is prepotent on all age levels: if a person is dominated by hunger, his/her whole philosophy of future tends to change, as the person's whole existence revolves around obtaining food. This was evident in this study, as 50% of the respondents indicated how they deal with the problem of hunger:

*"Sometimes we have to go from house to house asking for food."*

*"If there is nothing to eat in the house, I sometimes had to go to my other relatives even though they sometimes get tired of me. They are also struggling and if I tell them that I am hungry, they become irritated and complain that I have come to finish their food. They would tell me that there is no food, but I would stay until they have given me something to eat."*

*"There is no food most of the time, and this makes me worry a lot. I sometimes feel like leaving school so that I may be able to look for work."*

*"On Saturday I am always at the taxi rank, working as a taxi conductor, so that we can get money to buy food."*

*"Sometimes I clean gardens of people that I attend church with. And they too pay me and so we sometimes get some food. Sometimes I would wash cars to get money for food."*

These actions taken by respondents are in accordance with what was reported by Maslow (1970) in Meyer *et al.* (1997:440) that if a person is dominated by hunger, his/her whole philosophy of future tends to change, as the person's whole existence revolves around obtaining food. In this study some of the respondents had to work part-time so that there can be bread on the table, while other felt like leaving school in search of a job as a result of lack of food.

The findings of this study are similar to the findings of Mturi, Mazibuko, Ncama and Nzimande (2001:40-45) about child labour. All the children in their study pointed to the lack of food as their motivator for their decision to work, just as was the case in this study. Thus, they would diminish their already meagre opportunities for education and become family breadwinners, and their escape hatch from poverty will then become firmly shut. This situation further indicates the explicit relationship between economic needs and physical needs.

### **3.6.2 The need for clothes**

Clothes are things such as dresses and trousers that people wear to cover, protect or decorate the human body (Pearsall, 2001:270). Protection and comfort are basic physical needs to which clothing responds, and people are born with basic or primary needs that are satisfied by clothing (Foster, 1990:43-57).

The respondents reflected clothes for the purpose of comfort and protection as a need during the interviews. As illustrated in Figure 3.1, much emphasis was placed on school attire for winter:

*"I do get cold in the mornings because I don't have a school jersey. We get suspended from school if we wear private jersey."*

*"I don't have school shoes, and I cannot imagine myself going to school kaalvoet (bare-footed)."*

*"I need winter uniform and I don't think grandmother will be able to buy it."*

*"I don't have school shoes and I feel sad because know my mother is unable to buy me shoes."*

The findings in this study were similar to what was reported by Cullinan (2001:15), that children affected by HIV/AIDS may sometimes have school clothes, but in most cases these are very old. Furthermore, because of non-availability of shoes, some of them had to tramp a two-hour journey to school bare-footed. Just like the respondents in this study, Cullinan's subjects said: *"If we can just get food and clothes. We have some clothes that our parents bought, but they are very old."*

While some of the respondents had to find some means to get shoes, one respondent decided not to go to school. This was explained:

*"I have asked the children of one of the teacher, the one that I always clean her garden for their old shoes. I have send them for repair ... and after repaining them, I will then have something to wear to school"*

*"They (schoolteachers) will want us to have winter attire too, which I don't have, and that is why I prefer not to go to school."*

Other purposes for clothing were complex, as they relate to socio-psychological needs. These socio-psychological needs for clothing are related to inner self and relationships with other people, of which the main concerns are self-image and recognition (Foster, 1990:43-57).

As illustrated in Table 3.2, the need for clothes was thus not related to their basic need of covering and protection. They felt that they must wear something suitable for church:

*"My mother does get some grants for being ill, but we struggle to get clothes, because she uses the money for her medicines. I don't have clothes to wear to church."*

*"I don't have clothes to wear while I am at home, but for now my main concern is clothes to wear when I am going to church."*

*"I don't have clothes, the last time I got new clothes was when he was still alive and they are now torn and some are too small, so I have given them to my little brother."*

These findings correlated with what was reported by DeLong and Fiore (1994:100), namely that clothing has aesthetic appreciation, as it can function symbolically and referentially by assigning standards to clothing depending on culture.

The findings of this study further emphasized that some of the clothes were needed for conformity purposes related to socio-psychological needs for clothing:

*"My grandmother always promised to buy me some shoes, but that promise, I know will not happen. She says shoes are expensive."*

*"I always envy my friends, because they have beautiful clothes and they look down at me and some of them even say I cannot wear nicely like them. I always tell my grandmother that I too would like to look like a decent person."*

*"At least I must have a pair of certain clothes, so that I too can feel I am part of and be recognized among my friends."*

The descriptions above accord with what is described by Johnson and Foster (1990:43-57) and van Wyk, Erlangsen, Kruger, Gelderblom, Dostal and Vergnani (1984:123-125) about the socio-psychological need of clothing, in that the appearance of a person is determined by the way that person dresses. Certain things can be said about a person in relation to the way that person dresses. In this study, the respondents expressed a need to conform: to feel comfortable and accepted among their peers, and also showed an intrinsic desire to be beautiful.

The need for clothes according to the responses in this study, was thus related to inner self and the relationships with other people, of which the main concerns were self-image improvement and recognition to keep the individuality as a person, just as indicated by Johnson and Foster (1990:43-57).

### 3.6.3 Need for shelter

Shelter is a place that gives protection against unpleasant aspects of life (Pearsall, 2002:1320). Respondents reported different things with regard to shelter (see Table 3.2). These ranged from having their own house when they grow up as well as having a safe home where no one can steal, while some were worried about the loss of their home assets.

Studies have shown that terminal illness or death of parents because of HIV/AIDS has unpleasant consequences for the surviving children. In most incidents, children have to narrate in their minds how to learn to live alone, while at times there will be relocation to another place, probably to the grandparents (Ayieko, 1998:11-21). This phenomenon also prevailed in this study. Even though the respondents showed acknowledgement for having a place to stay for now, there was still a fear of *"what happens then if we loose grandma."* As indicated by this respondent, there was also a need to have a place of their own:

*"We will stay with grandmother until we are grown-up; from there we will want to have our own house, but if granny also dies we will have to stay in our mother's mk'huk'hu (shack house) by ourselves."*

Studies have indicated that when children are either on their own or have relocated, there is a tendency of unethical stripping children of the remainder of the parental assets by relatives, family friends or neighbours, either by taking the advantage of the unsuspecting and naïve survivors or by intimidating the survivors (Loewenson, 2001:10-21; Richter, 2001:32-33; Ayieko, 1998:11-21). This was a similar finding in this study, as respondents indicated that their neighbours were not happy with what they have, while others indicated that the relatives claimed the furniture in the house:

*"After funeral, our stepfather came to ask for this furniture, claiming that he also paid his money when it was bought."*

*"This house is not safe, because now and then people just break in and steal. Most people around here are not happy that children like us can have this kind of furniture that my mother has left for us."*

The phenomenon of asset-stripping by relatives and family friends was not the only way in which the respondents were losing their household assets in this study. One aspect was in the form of selling in order to make ends meet:

*"The other day she (their mother) wanted to sell radio and I pleaded with her, as it was the only thing in the house to listen to, since the TV is already gone. I am not happy about all this ... If we are going to lose everything like this, we would rather live the way we are, rather than her selling things."*

The descriptions in this study are in accordance with Loewenson's (2001:10) findings. But what is more worrying is that once these assets are disposed of by way of selling, they reduce the possibility of being recovered and rebuilt, and this will undermine the future survival and not just increase poverty but widen the gap between the sick and the poor. As Richter (2001:32-33) too comments, the households will become progressively more affected as children may suffer loss of their homes or home assets through the sale.

The loss of assets because of selling, so as to cope with the economic hardships was, however reported less often in this study, as only two respondents reported this during the interviews. This small number of respondents resorting to the selling of the household assets, could be related to the fact that other respondents' households were too poor to own any assets. This was as identified by Booyesen, van Rensburg, Bachmann, Engelbrecht and Steyn (2002:13) in their study in Welkom and QwaQwa in which the households were also too poor to have any household assets to sell.

#### **3.6.4 Need for heating fuel**

Fuel is any material such as coal, gas, or oil that can burn to produce heat or power (Pearsall, 2002:571). This was one of the needs identified during the interviews. One respondent mentioned that there are times when their home is without electricity and that the paraffin, which is a liquid fuel, is being used sparingly.

*"Sometimes you will find our home dark, because there is no electricity. And when is dark during the night I cannot do anything, not even study for test or do my homework. We have to save the paraffin to warm water for bathing before going to school."*

The problem of fuel was also a similar finding in Eyeington's (2001:10-11) study, in which the families in her project in Swaziland were in need of sufficient fuel for cooking. Though the need for fuel in this study was for academic purposes and heating, there is a possibility that it was also needed for cooking. As this was an in-depth interview, respondents only emerged with their most important needs.

### **3.7 ECONOMIC NEEDS**

The basic economic needs of human beings extend over one or more functions that are related to the creation, legal appropriation and market exchange of goods and services. Traditionally these needs have been satisfied through access to labour, land and natural resources. In the modern world, access to physical and financial capital is a prerequisite of an independent and productive economic life (Gorga, 1999:2-3).

The economic needs reported by the respondents are as illustrated in Figure 3.2. These have been quantified on the basis of the number of respondents who made reference to the same themes and in the same categories (see Table 3.4). This is done only to illustrate how important these needs were, and should not be interpreted as in quantitative studies.

**TABLE 3.4: Economic needs of children affected by HIV/AIDS in order of their frequency (N=10)**

<b>NEEDS</b>	<b>FREQUENCY (F)</b>
Financial capital	
Money needed for:	
❖ School fee	8
❖ School tour	7
❖ School books and stationery	5
❖ Church tour	4
❖ Thanks-offerings at church	3
❖ Medical expenses	3
❖ Burial society	1
❖ Insurance policy	1
❖ Transport	1
Physical capital (education)	
❖ I do not want to miss classes	7
❖ We want to be educated	5
❖ I have to work	3

The economic needs as reported by the respondents in this study ranged from the need of money: as a mode of exchange, the desire to be educated as a way of acquiring knowledge and building future economic stability.

As explained by Gorga (1999:2-4), there is no economic activity without financial capital like money or other liquid assets as a means of exchange, and equally essential as financial capital is the physical capital, whether in the form of a pen or computer, as well as acquisition of specialized knowledge for production of other goods and services.

### **3.7.1 Financial capital (money)**

Chandler (1969:2) states that one need not be an economist to be actually aware that money plays an important role in modern life. From personal experience one knows that the process of earning a living is a process of acquiring and spending money



Money as medium of exchange to buy food, school uniforms, church choir uniforms, school fees, school and church trips, church thanks-offerings, as well as for medical expenditure for the ill parent were aspects that were identified by the participants during the interviews. This need was expressed by all the respondents, showing various ways in which the money would be spent:

*"We (including brother and sister) don't have uniforms and our school fee has not been paid, and when there are school trips we are unable to go like other children because there is no money."*

*"I am unable to buy a uniform, because there is no one working."*

*"There is no money in this house ... there are times where there is totally no money in this house. And you will find that there is no money for mealie-meal ... there is totally nothing ... (to eat)."*

*"I am a member of the church choir. And I struggle with money to pay when there are trips to take."*

The findings of this study are consistent with the findings by Ritcher (2001:32), in which the average income falls drastically when one of the family members has AIDS. As also identified by Ritcher (2001:32), the economic impact quadruples and families go into debt as health care expenditure also increases.

*"We sometimes have to borrow money so that my mother can be able to see a doctor and be able to hire a car to take her to a doctor. And at the end of the month, when she receives her sick grants, we have to pay back the borrowed money and there won't be anything left to buy my school uniform."*

The findings of this study accorded with Sliep, Poggenpoel and Gmeiner's (2001:63) findings that HIV/AIDS brings financial burden and crisis to the affected household, and that in most cases, school fees for children become the extended family's burden. In this study, grandparents were the ones who were burdened:

*"I need winter uniform and I don't think grandmother will have money for that ... and the other problem is: I am still far behind with payments of the thanks-offering at church."*

*"I managed to pay R50.00 for the school fees, and my grandmother has not been able to pay the rest of the school fee. If she is forced to pay now, she will have to borrow the money."*

The issue of declining household income was also highlighted by Booysen *et al.* (2002:11-12) in their study, that because of reduced income and unemployment in these households, borrowing followed by no inheritance of lump-sum payment following death is prevalent, and this further drives the family from poverty to destitution:

*"We had no money to bury her, as there was no money for her coffin. Then I had to borrow money just to get a coffin, but luckily the person from whom I lend money later said I must not repay back his money."*

The findings of this study support the findings of Smart (2000:22), Wekesa (2000:12-14) and Foster (1997:4-5) in that the income of their HIV infected parents was reduced owing to medical expenses. Furthermore, with the death of the parent the funeral expenses deplete the resources, and the children are then plunged into an economic crisis and insecurity.

### **3.7.2 Physical capital (education)**

According to Gorga (1999:2) there is no economic function that can be carried out today without physical capital. Byrns and Stone (1981:621) say that investment in new machinery or other physical capital requires sacrifices of current potential consumption, so that a higher level of future incomes and consumption might be realized. Acquisition of new skills through education requires similar sacrifices. Byrns and Stone (1981:621-622) further comment that even though the benefits for better future income derive from college education, primary education makes one semi-civilised while high school civilizes one further.

As indicated in Table 3.4, the respondents were of the opinion that lack of education would affect their future, as they may not become what they would like to be. They seemed to have a feeling that education will lead them somewhere where life will be better. This was as indicated by Higgs (2000:5-6), that education safeguards the future economic stability of an individual, and this concurs with what one respondent said:

*"I like being at school ... but my school fee has not been paid. I really feel bad, because I am going to be far behind with most subjects and at the end I won't be able to pass and be what I want. Because I want something better out of my life at the end."*

Other respondents in this study showed interest in their siblings' education as well.

*"I want to continue with my education and I want my siblings to continue too with their education. I want my younger sister to finish her schooling."*

They reported to feel unhappy about missing the classes, as from time to time, they are suspended from school. Their statements exemplify their eagerness for further knowledge or education:

*"We do miss the lessons ... because when we are suspended, we are not being allowed to come to school until the school fee has been paid."*

*"My school uniform is not complete and I am always sent back home to go and change ... and I feel sad, because I miss a lot of lessons if I am not in the class."*

The eagerness for education shown by the respondents is in accordance with the findings of Gilborn *et al.* (2001:18) in which the AIDS pre-orphans and orphans reported to be happy in being in school, and that missing school and doing poorly in school was associated with feelings of sadness and social isolation. Furthermore, respondents confirm Higgs's (2000:5-6) explanation that education is a tool for better economic stability – one of the proponents of a productive economic life – and there is no incentive for a child without a good education.

Commenting about education, the United Nations Educational, Scientific and Cultural Organization (UNESCO) and UNICEF (1999:1-2) indicated that education is the foundation for lasting change, and its impact extend far beyond a surface level: broadening employment options, increasing income levels, improving overall health and well-being, helping prevent the spread of HIV/AIDS, and stabilizing interpersonal ties. No matter how important education could be, to some respondents the line of demarcation has been drawn, as the future education plan seems bleak:

*"The other problem is ... mm ... because now my mother is sick, I don't think I will be able to go to the university next year. I received application form from the university and I would like to apply for the bursary. But I cannot be allowed to apply for the bursary, because I must first fill application forms. And they need R50.00 to be posted with and my mother cannot afford that money."*

Being concerned about their education, the respondents indicated that they sometimes have to do piece-jobs in order to pay for their own education, as well as their siblings' education, and also to pay for other school requirements:

*"I want to carry on with my studies even though a lot of my friends are advising me to leave school, because we are struggling. And for this reason, on Saturday I am always at the taxi rank, working as a taxi conductor, so that I can get money to pay for the school fee ..."*

*"I sometimes braid people's hair ... and with the money I would sometimes buy things that are needed at school like books and pay for other activities happening at school."*

*"I have cleaned one of the teacher's gardens for a pair of old shoes from her children. I have taken them for repair and when the school opens I will be having school shoes, because if we go to school wearing shoes not meant for the school, the teacher sends us back home."*

The findings of this study indicate that the children affected by HIV/AIDS don't just sit and wait for help from somewhere. As also reported by Gilborn *et al.* (2001:19) and Ayieko (1998:27-28), the AIDS pre-orphans as well as orphans find ways of generating money, by either working for wages or initiating projects for generating money. However, these methods of generating income are short-lived as they are based on small-scale and lack of skills. These methods seemed to have little or no profit because besides their added efforts, the respondents in this study were still being suspended from school.

This may be as reported by Ayieko (1998:27-28), that projects that were supposed to generate money, were based on small-scale business, as well as lack of managerial and technical skills. The same problem could have prevailed, as cleaning of gardens, washing of cars, and plaiting of hair in this study were only meant for acquiring quick cash.

Commenting about the children affected by HIV/AIDS and generating of money, Wild (2001:9) indicated that these can place the pre-orphans and orphans at risk for abuse, exploitation and engaging in a dangerous lifestyle as they attempt to provide for their families and themselves. This was, however, not a problem in this study, as none of the respondents reported any abuse or exploitation.

The findings in this study support other studies, namely that HIV/AIDS has a disproportionate impact in poor communities. As the illness is likely to be prolonged, the families are likely to be destitute by the time the parents die. In most cases, children are left without any inheritance, and they may be forced to leave school because their families cannot afford school fees or uniforms (Wild, 2001:8-9).

### **3.8 PSYCHOSOCIAL NEEDS**

According to Reber (1995:620), the term psychosocial is used to cover any situation where both psychological and social factors are assured to play a role. Louw and Edwards (2000:500) further explain that psychosocial needs are important for general social and emotional adjustment, and influence the individual's social relationships and personality formation. HIV/AIDS is associated with complex psychosocial effects like stigma; rejection; fear of the unknown; social isolation; as well as impaired quality of life and the need to make remarkable lifestyle changes. These effects are felt not only by the suffering parent, but by their children as well: just as the rights of children are inextricably linked to their parents, so are their sufferings and happiness (John & Ndebbio, 2002:59).

The results in this study suggested various ways in which the respondents felt the needs related to the psychosocial aspect. The needs have been quantified on the basis of the number of respondents who made reference to the same themes and in the same categories as indicated in Table 3.5. The purpose of this quantification is to illustrate how important these specific needs were to the respondents in this study.

**TABLE 3.5: Psychosocial needs of children affected by HIV/AIDS in order of their frequency (N=10)**

NEEDS	FREQUENCY (F)
<b>Relationship with:</b>	
<b>Relatives</b>	
❖ Unreliable alliance	10
❖ Lack of support	9
❖ Rejection	3
❖ Conflicts	3
<b>Community</b>	
❖ Lack of understanding	5
❖ Rejection	2
<b>Teacher/school</b>	
❖ Rigid school policies	7
❖ Lack of understanding	4
<b>Love and belonging</b>	
❖ Friends	8
❖ Schoolmates	5
❖ Social clubs	4
❖ Church	3
❖ Gangs	3
<b>Self-image</b>	
❖ Presentable	6
❖ Being part	3
❖ Recognition	3
<b>Counselling</b>	
❖ Lack of information about HIV/AIDS	8
❖ Not coping	4
❖ Worried about illness of parent	4
❖ Incomplete grief process	4

The Southern African AIDS Training Programme (2003:1) has identified that children are not just bystanders in the AIDS pandemic, whether infected or affected, they too experience psychosocial needs that are frequently neglected. The sub-categories of the psychological needs as described by the respondents will be discussed, and their themes will also be given as direct quotes.

### **3.8.1 Need for relationships**

A relationship is a connection between people with well-defined social roles, founded upon strong emotional ties and a sense of commitment (Reber, 1995:657). The need for relationships is deeply embedded in our created nature. People owe their existence not to impersonal forces, but to a personal Creator Himself who said, "*it is not good that man should be alone*" (Genesis 2:18).

#### **3.8.1.1 Relationship with relatives**

Wild (2001:11) identified that children react commonly towards the terminal illness and death of a parent, and this ranges from hopelessness, loneliness, confusion, anxiety and fear of being alone. The respondents in this study exhibited some of these reactions. It might be possible that these reactions could have contributed to the fact that children affected by HIV/AIDS in this study looked for the extended family's support.

In African culture, a family unit is not limited to a nuclear unit. It extends to various other family members according to the needs arising in that community. The extended family is one of the valued structures within the African family system (Munodawafa, 2002:7-8). If there is illness in the nuclear family, the whole extended family becomes affected. A crisis for one means a crisis for all. If a child is orphaned, there will always be the next parent to step in. He will raise the child as his own. The group thus participate in all the decisions taken; therefore a family relies on and becomes dependent on this group for both physical and psychosocial support (Munodawafa, 2002:7-8).

However, this extended family structure, no matter how important it may seem, raised false hopes for all the respondents in this study. As illustrated in Table 3.5, all the respondents felt that they were deserted especially at the time of crisis. Some of the respondents reported that they made some advancement to these kin groups, but they were rejected:

*"We do have other families ... my uncles. They don't even think about me when they enter the shops. They do nothing for us. They don't even come to see us even if I can phone them, to come and see my mother, especially the time when she is seriously ill. They don't come. They would stay at their homes, because my mother's illness is not their problems. It is my problem ..."*

Sliep *et al.* (2001:63), support these descriptions and are of the opinion that, even though relatives are regarded as a valuable support system in times of difficulty, the HIV/AIDS pandemic has declared war against this system. According to Sliep *et al.* (2001:63), HIV/AIDS to some of the relatives means death, and if death thus happens, it means that the sick person will never be able to return the favour to the relatives that did provide, either financially or in kind. This was confirmed by one respondent:

*"My aunts have changed. The time when my father was alive, they used to be happy when I visited, because he used to help them a lot. But nowadays, they insult me, if I come to their house. And I have stopped visiting them."*

Besides being rejected, the respondents in this study indicated that even the visits that these relatives used to pay them have also ceased with the illness and death of their parents:

*"Our relatives don't come here regularly. But at that time while my mother was working, they used to say they have a sister in Mangaung and they used to come regularly. Now my mother is not working and she is ill, I think it is a good reason for them to come and visit, but they don't come. They no longer buy us things they used to buy for us."*



The reasons for not visiting in this study were not known to the respondents, but it was clear from the interviews that the respondents would have appreciated the visits from the relatives. The findings of this study were similar to Ayieko's (1998:15-17) finding, as there was lack of support with regard to the relatives visiting the children affected by HIV/AIDS. According to Ayieko (1998:15-17), this lack of support was related to the fact that relatives were staying at different locations with the HIV/AIDS affected children, and this was associated with high travelling cost.

Besides being unvisited, the respondents were no longer accepted in their extended families. This was also identified by John and Ndebbio (2002:61), that once the diagnosis of HIV becomes known by the most valued and satisfying sources of social support, the social support is likely to be reduced. In John and Ndebbio's study, the subjects even reported some degree of alienation, as reported by the respondents in this study as well:

*"The man that was staying with my mother, moved to his house when my mother started to be ill. He did not even come when we told him about my mother's death. He did not come or bring my other sisters (half sisters) to our mother's funeral."*

*"We do have relatives, but they don't give us or do anything for us even though they know that my mother is sick and I don't know why they are doing this."*

The statements by the respondent echo the need for reliable support in times of crises, especially in times of illness and death. No matter how they long for the support from their relatives, the respondents in this study felt that they received little or no support from their relatives during the illness and death of their parents. This may be in agreement with what was identified by Ayieko (1998:15-17), that the current urban lifestyle has a tendency to emulate the Western nuclear family, and plays a major role in eroding the extended family support system. Mangaung, as other urban areas in African countries, is surrounded by many urban slums in which most respondents in this study reside. These are likely to be characterized by a weakened extended family support system. The case study done by Mturi *et al.* (2003:20) in KwaZulu-Natal, identified that orphaned children living in the city had no other family members to look after them as compared to those staying in rural areas,

and this was also the case in this study. These scenarios clearly reflect that the African urban life has adopted the western nuclear family.

The study done by Rehm and Franck (2000:69-82), however, differs with the findings in this study, as the extended families in their study were participating in the care of children during the illness of the parent. However, this was based on the fact that parents made prior arrangements for the care of the children. For this reason, the children in their study valued relationships with other extended family members, and often talked about aunts, uncles and cousins in a friendly way.

### **3.8.1.2      *Relationship with the community***

When one is a member of the community, one develops a sense of belonging through interaction with the members. This interpersonal interaction and mutual acquaintance give community coherence, in such a way that an individual in the community feels that he/she has a role to play, and in return, feels spiritually dependent on the community, because the community thus satisfies his psychological needs such as social intercourse and friendship (Mellish, 1982:20).

The respondents in this study got a response different from that described by Mellish, as five respondents indicated a lack of support, as well as rejection by the community around them during the illness and death of the parents:

*"They say I too, have that disease she is suffering from. Sometimes even other children avoid me. If I start playing with them, they would walk away saying that I might infect them with my mother's disease."*

The findings of this study support Raufu's (2002:9) findings that when parents are known to be dying of HIV/AIDS, the affected children become ostracised by the neighbours and relatives, and at the same time, children in the neighbourhood are not allowed to play with them. According to Raufu (2002:9), the reason for ostracism is based on the myth that AIDS will pass to their children. Thus, the potential caregivers as well as the traditional coping mechanisms diminish.

These misunderstandings or rejection as stated by the respondents, may also be as viewed by Zerwekh (2000:47-60), that people with HIV/AIDS force themselves into isolation because of embarrassment and humiliation, while in response to that, society abandons them with a connotation of potential harm. This can be reflected onto the affected children as they may also isolate themselves or be discriminated against by other children:

*"I feel bad and my mother also feels bad about her face, especially when people have started to dislike her and say that she has got AIDS."*

*"The people around here talk about my father. And I become hurt when they say he was suffering from such a disease...."*

This lack of understanding and support as well as marginalization by the neighbouring community as described by the respondents, could largely be ascribed to the stigma. This reaction by the community may sometimes force the affected children to isolate themselves, and this can also obstruct the expected support from the communities (Zerwekh, 2000:47-60).

The findings of this study further revealed that the communities in which the respondents live do not allow individuals in the community to feel that they have a role to play, and in return, make an individual feel psychologically dependent on the community, because it satisfies his psychological needs such as social intercourse and friendship as described by Mellish (1982:20). This was revealed during the interviews:

*"Every time when there is theft committed around our vicinity, I am always a suspect...."*

*"They gossip about the death of my mother ..."*

The findings in this study correlate with Ayieko's (1998:17) conclusion, that in this era of the HIV/AIDS pandemic, children are no longer the collective responsibility of communities, a legacy that has been historically associated with child rearing in Africa. This fading or faded devotion and attachment is thought to be on account of the discouraging number of deaths in the communities due to HIV/AIDS, as each family tends for its own survival. According to Harber (1999:8), modernization, urbanization and poverty are factors that are responsible for the weakening of the traditional support system of South African life. Based on the observations made during the visits to the communities where the respondents in this study reside, the factors as identified by Harber prevailed.

### **3.8.1.3      *Relationship with teachers and school policies***

The respondents indicated a lack of understanding from the side of teachers, based on the rigid school policies as they were suspended from school if their uniforms were not complete or their school fees unpaid:

*"In most cases I am being sent back from school, because I don't have school shoes."*

*"Like now when the school re-opens, all those whose school fee is not paid are going to be suspended from school, and I am going to be suspended too."*

*"If we (including the siblings) go to school wearing shoes not described for school uniform, the teacher sends us home to go and put on school shoes. Sometimes we have to stay home for some days until we have those specific shoes."*

In some cases, the respondents had to walk a long distance to school in spite of the weather conditions, and to their amazement and disappointment for their effort they would find the school gates locked for latecomers:

*"I don't have money for transport to school and if I happen to arrive late, I will have to come back, because the school gates will then be closed."*

The respondents also complained about rigid school policies and teacher's misunderstanding:

*"If we have not paid the school fees, we won't be allowed to take our reports home. They remain a school property."*

*"My uniform is incomplete and there are times that we are not even allowed to be within the school premises."*

Literature is not specific about the teachers' lack of understanding as well as rigid school policies. However, the findings of this study were as Cullinan (2001:15) reports in the Sunday Times, that there are few teachers who do not send children home for unpaid school fees or incomplete school uniform. Cullinan further indicated that in the majority of cases, these children would have walked a long distance barefooted, only to be sent home to no one, as the child himself/herself is the head of the household.

However, these school policies do not conform to the South African School Act, No. 84 of 1996 with regard to admission and compulsory attendance of a learner in public schools. According to this act, no pupil can be denied attendance of a public school; however, the phenomenon of suspending pupils from the school is prevalent in many schools, as reflected by the respondents' descriptions.

Some of the respondents' claims accord with the comments made by World Bank and UNICEF (2002:24-25) about HIV/AIDS and the school attendance of the affected children: ***"When there is an illness or death in the household, the available financial resources tend to be used to care for the sick or for funerals, thus reducing resources allocated for children's schooling. The outcome is either a delay in enrolment (in most cases) or no enrolment at all. Attendance at school also declines, especially as the children have to work and care for the sick parents. Performance suffers as a result of absenteeism and a lack of parental care and support."*** Some of these phenomena also prevail among some of the respondents in this study.

### 3.8.2 Love and belonging

Love is an enduring sentiment towards a person, producing a desire to be with that person, and a concern for happiness and satisfaction of that person, while belonging is the feeling of inclusion or acceptance (Reber, 1995:90, 425). According to Rotenberg and Hymel (1999:3), belonging is the need to establish social bonds with others who care.

As illustrated in Table 3.4, all the respondents indicated that at some stage they do want to belong and be loved:

*"I don't like to be always in the house. I wish I could visit other children, play with them at the streets and if there is money to go to the shops with them. But, because of the headache and this miserable feeling, I am always in the house."*

*"I play chess at school and if there are trips, I am always unable to go with other chess player if the school does not pay, because my mother won't be able to pay."*

*"I don't want to go to church just for the sake of going to church. I want to take part too. So if I don't get things that are needed at church, I think there is no need of me going to church."*

*"The problem in the house is my uncle. Whenever he is drunk, he tells me that I am not his mother's child." (The respondent is staying with the uncle and grandmother.)*

*"I feel bad especially when people started to dislike her saying she has got AIDS. Sometimes I become scared of meeting people."*

*"I have friends in the neighbourhood who like to drink alcohol. They say I consider myself to be a goodie-goodie, because I don't drink alcohol."*

*"And sometimes I feel like joining some gangs at school, but my conscience cannot allow me to join ..."*

Eight of the respondents (80%) indicated that they could not be with friends as they would love to be. There is also a sense of partial fulfilment as a member of the school, church or social club because of a lack of contribution. This is what the other respondents had to say:

*"My mother is unable to pay for school trips she always say she won't afford and I always feel hurt, because if my team wins I feel I must win with them and if my team is defeated, it is as if I am to blame, because I was not around to help them."*

*"I am unable to go away and play with friends even when friends ask me to go out with them, I don't feel comfortable to go."*

The statements made by the respondents accord with what Ritcher (2001:33) indicated, that children affected by or orphaned by HIV/AIDS find themselves separated from their friends owing to increased workload, exhaustion, social isolation related to insecurity and stigmatization, as it is often assumed that they too are infected with HIV. This was the case with one respondent in this study who said:

*"Sometimes other children avoid me. If I start playing with them, they would walk away, saying that I will infect them with my mother's disease."*

Literature is not quite specific about the need for love and belonging in children affected by HIV/AIDS. However, it has been identified that it is normal for people to want to create conjunctive emotions of love; wanting to be with other people. Therefore, effective satisfaction of psychological needs, belonging, fun (enjoyment), and freedom, result in a sense of control or becoming a fully functioning person (Corsini & Wedding, 1995:63, 294).

Commenting on this, Rotenberg and Hymel (1999:155-156) said that inability to satisfy the need to belong, whether because of personal or situational constraints, is likely to result in personal difficulties such as negative conclusions about self, others or both, and this was the case in this study as some of the respondents said:

*"Some of my schoolmates know that my mother is sick, and they say my mother is ill and not working. I feel bad when they talk about their parents."*

*Every time there is theft committed around our vicinity, I am always a suspect."*

While other respondents felt that they were being judged by others on the basis of having a parent who is either ill or dead, others isolated themselves because of embarrassment and humiliation. As identified by Wild (2001:10), this vast conspiracy of silence because of the prevailing stigma still surrounding AIDS, and for this reason children may cut themselves off from social support, and in some cases they may even change friends, as they may not want their friends to know about their parents' diagnosis. This was the case with one respondent in this study. The respondent did not change friends, but did not want the friends to know about the parent's diagnosis:

*"Most people here are saying she (mother) has got AIDS and this makes me feel bad. Sometimes I even become scared of meeting people ... I am scared because these people might say my mother have AIDS in the presence of my friends."*

Studies have also shown that that people with HIV/AIDS or affected by HIV/AIDS, force themselves into isolation, and this may increase the social isolation and could deny them access to essential services like education (Zerwekh, 2000:47-60).

Most of the respondents indicated that they were unable to attend social events like school trips, chess clubs with other friends or schoolmates. This phenomenon was also identified by UNAIDS and UNICEF (2002:10-11) and Sliep *et al.* (2001:62), that with the impact of HIV/AIDS, fewer families could afford to send their children to school. Thus, one can understand that if a parent or caregiver were unable to pay school fees, how would she be able to pay for school trips and other requirements needed at church or church choir.



### 3.8.3 Self-image

Self-image is defined as the imagined self; the self one supposes oneself to be. This self is further distinguished as three types: An image of oneself as one is; an image of oneself as one should be; and an image of oneself as one would like to be (Meyer, Moore & Viljoen, 1997:420; Reber, 1995:703).

Most of the respondents as illustrated in Figure 3.3 indicated that they would like to be like other children:

*"I wish I too can be like other children especially now in winter. I don't have sweaters and training shoes for the school."*

*"I don't look like other children. I am always on the black list as I am always wearing a black skirt; the colour that is no longer used at the school."*

*"I always envy my friends, because they have beautiful clothes and they look down at me and some of them even say I cannot wear nicely like them. I always tell my grandmother that I too would like to look like a decent person."*

*"At least I must have a pair of certain clothes, so that I too can feel I am part of and be recognized among my friends."*

The sense of self-worth in children affected by HIV/AIDS is insufficiently documented or not at all. However, Allport (1961) in Meyer *et al.* (1997:420-421) indicates that the opinion of others and one's own direct experience of oneself form the basis for most adolescents' self-image, and these could have been the case in this study, as the respondents were aged between 11 and 18 years.

Meyer *et al.* (1997:420-421) view is well supported by the respondents in this study, as they described how other children viewed them. They suspected that other children had negative feelings about them, based on how they evaluated themselves:

*"I am unable to be at the standard of other children, since the illness of my mother that is why sometimes I feel uncomfortable to be with friends."*

These descriptions are as Rotenberg and Hymel (1999:155-156) comment, that inability to satisfy the need to belong (whether because of personal and situational constraints), is likely to result in personal difficulties such as negative conclusions about self, others or both.

Some of the respondents in this study further felt that they wanted to be recognized and be as presentable as they would like to be. This was as described by Pawlik and Rosenzweig (2000:269), that adolescents have a conception of what they would like to be – that is an *ideal self* – and that unfavourable self-evaluation may be associated with depression or other negative outcomes.

#### **3.8.4 Counselling**

According to Hornby *et al.* (2003:1), counselling is seen as a skilled and principled use of a relationship to facilitate self-knowledge, emotional acceptance and growth and the optimal development of personal resources, with the overall aim to provide an opportunity to work towards living more satisfyingly and resourcefully. Providing information is an integral part of counselling, and according to Hodgkinson and Stewart (1998:140) it must be based on factual information, as the survivor may experience support as well as potential benefits from being knowledgeable.

The findings revealed that respondents need counselling, as they exhibited signs of not being able to cope with illness and the death of their parent. Guilt, resentment, exhaustion as well as disappointment were signs exhibited by the respondents.

*"My mother at times becomes seriously ill and when I am at school, I would start to be worried as to what might be happening at home, and on my way home I would cross the roads without thinking without looking for the oncoming cars."*

*"I was unable to be away or play with friends. I was always with him and thinking about him. All these make me sad even now especially as I was hoping that he would be cured. What always come to mind is that he was unable to eat or do anything for himself. He sometimes used to spend three days without eating."*

*"I don't concentrate well in class. I am always thinking about problems at home, as to how my mother is: Whether she is still alive or not, if I am going to find her admitted at hospital. I have got a lot of things going in my mind. Besides that I have to be always in hurry, for when I get home from school, I have to clean the house, cook, do my homework and go to the choir practices at church. Everything in the house has to be done by me."*

The respondents' statements accorded with the South African AIDS training programme's (2003:23) findings, that children react differently towards suspicion of HIV/AIDS in the family. As also happened in this study, some of the respondents chose to ignore the fact that their parents had HIV/AIDS while some were worried about the parent health, and some were faced with added responsibility which resulted into a significant drop in school performance. Some of the respondents put the blame on themselves:

*"I worked as a taxi conductor on weekends and sometimes after school too I would work, so that I could buy my mother the pain pill. The other day I did not have money for her pain pill and on that day she was unable to talk. She was breathing with difficulty and I called the ambulance. She was then taken to hospital where she died after three days."*

The findings in this study were as identified by UNAIDS (1999:5), that children find themselves thrust in the role of mother, father or both – doing the household chores, looking after siblings and caring for the ill or dying parent, experiencing stress that would exhaust even an adult. Thus the children whose parents have HIV/AIDS begin to experience loss, sorrow and suffering long before the parent's death. As pointed out by Nicholas and Abrams (1992:3478), children affected by HIV/AIDS are effectively orphaned prior to their parent's death, because of tragic aura like poverty that surrounds these young survivors.

Some of the respondents had to do other household chores that are supposed to be an adult responsibility; however, their most severe stress and suffering was caused by seeing their parents in pain:

*"I am cannot be happy .... I am never happy at school. When other school children are happy, I always feel very sad ... that is why I would prefer if my mother were not around. Sometimes I do ask God, as to why He is not taking her, because she is really suffering."*

This scenario as described by the respondents was also reported by UNAIDS (1999:5), that children live long periods of uncertainty and intermittent crises as the parent slowly sickens and ultimately dies as the HIV infections progress from mild related illnesses to the life-threatening illness called AIDS. The children in this study too suffered depression, stress and anxiety as they lived through their parent's pain and illness. This was as described by Rotheram-Borus, Stein and Ying-Ying Lin (2001:768), that parents and children form an interdependent and interactive social unit; if one is affected, the entire family become affected.

The stressors of living through the parent's pain were not in isolation, as most of the respondents in the study also reflected the ambivalent feeling related to their actual suspicion regarding the parent's diagnosis, people's gossip as well as the actual physical state of their parents. Ledlie (1999:146) describes these types of phenomena as intervening conditions that act as catalysts in the decision to disclose diagnosis to the children. Ledlie (1999:146) indicates that when children seek information about HIV/AIDS, they use different strategies. They may either seek the information directly or they may use cues to illustrate their need. The South African AIDS training programme (2003:23) further indicates that if information about HIV/AIDS was not given to children in a simple way, they react by way of denial to the news, and this was expressed in the following statements:

*"I don't like when people talk about my father and that disease they were talking about. It is not possible that my father had it."*

*"My mother is not an ugly person, but since she became ill, she has changed. I feel bad and she also feels bad about it. Especially when people started to dislike her, saying she has got AIDS. Most people here are saying she has got AIDS and this makes me feel bad. Sometimes I am even scared of meeting people. I am scared, because if I am with other children, people from our neighbourhood might say my mother has got AIDS, but I know my mother does not have that thing."*

These descriptions sadly illustrated how the respondents were left to suffer in isolation in the name of being protected from discrimination. As described by Lyons (1998:4), this fear of discrimination, rejection or abandonment by other family or community members had lead to some families keeping the knowledge of HIV infection and AIDS a secret from the children. The respondents in this study were also left to suffer in isolation as they only watched their parents die and their families languish without proper information, except for gossips and assumptions based on the clinical picture of their parents.

This phenomenon of keeping secrets from the children is also clarified by Wild (2001:10), saying that HIV/AIDS is viewed by many people as a punishment for an "immoral lifestyle" such as promiscuity, and is always viewed with an irrational fear of contamination. That is why some of the children may be lied to or not told, ultimately causing them to be unable to understand or accept the cause of their parent's illness and death. As indicated by Smart (2000:13), Wekesa (2000:13) and Lyons (1998:4-5), adequate information will thus enable the children to make informed decisions about activities that could increase susceptibility to infection and prevent the vicious cycle of HIV/AIDS.

Other respondents further illustrated this need for information, where fear of being infected was demonstrated. As described by Ledlie (1999:146), the respondent was direct in seeking information about HIV/AIDS:

*"I am scared that I might be infected too ... especially, because she is coughing a lot and if ... I think I am always close by or sitting next to her, and I might be infected. Whenever I pass by, people talk, they say that my mother has such and sick illness. But even me too, I don't know if HIV can infect one just like that: say staying in the same house with my mother."*

*"The other thing is: I think my mother is ill too ... she is always worried and she is sweating a lot during the night. She used to be a very fat person, but she is now loosing weight and I am worried if she too dies, who will look after us."*

*"They said at the clinic that she had tuberculosis and they referred her to another clinic to some tests. After few months she died. She was not ill for a long time."*

The researcher accessed rather limited literature about providing children affected by HIV/AIDS with information regarding HIV/AIDS. HIV/AIDS information is known to be available and freely accessible. However, Lyons (1998:3) indicates that poverty is depriving people access to health facilities, schools and media, and it can also limit their access to information and education on HIV/AIDS, as was probably the case in this study.

Lyons (1998:3) indicated that in many societies, children were protected from information pertaining to sex and sexually transmitted diseases (including HIV/AIDS), thereby depriving them of the opportunities to understand the risk and danger they may be facing. This could have been the case in this study, as the respondents were all Africans, and information pertaining to sex and sexually transmitted diseases (including HIV/AIDS) is a taboo in African cultures (Ministry of Health and Social Welfare Lesotho in collaboration with World Health Organization, 1997:9).

Besides the need for information, some of the respondents were still unable to cope with the loss of their parent, no matter how long the parent had been dead. This was acknowledged thus during the interviews:

*"I miss my father ... Yes ... There were times that we used to have conflicts with him, especially while he was very ill ... I cannot concentrate well in class, because I always think about him ... and I don't like when people talk about my father and that disease they were talking about. It is not possible that my father had it ... yes, it is possible that people can be infected, but I don't like when they say my father was suffering from such an illness. My heart is always sore."*

*"I really miss her ... even now when people talk about her, I miss her, even though she was doing nothing for us. I saw her when she died ... I ... I ... I saw that she was not breathing and I went out to call granny.(crying) I believe I have forgotten about her ..."*

*"Grandmother used to ask her to come and stay here. She used to sleep out and I don't know where she was going, but she was my mother and I still love her, and I do miss her."*

The findings of this study confirmed that illness and ultimate death of a parent is thus a crisis for any child, and as Wild (2001:8) suggests, this crisis is more complicated for an AIDS orphan, as there are a set of material and psychosocial stressors which often accompany the parent's illness and death, hence their grieving process becomes such a problem.

Left thus, children affected by HIV/AIDS are likely to grieve in isolation with damaging effects. Clark (1984:633-634) reported that grieving in isolation is characterized by feelings of guilt, deterioration of health as well as psychosomatic conditions, if the bereaved talks or thinks about the loss. The respondents in this study demonstrated the same signs, and this is what the respondents had to say:

*"I don't know what is wrong with me ... I sleep a lot and I also have headache. I will start by feeling miserable and then the headache will start and then I will feel like sleeping. I don't know the cause of this, but whenever I play with other children, this will start. My younger brother also has these episodes."*

*"My younger sister always talks about our father. She would cry, saying that she wants him back. I always comfort her, but I too cry at times."*

*"I never stopped thinking about my dad, even when I cross the streets. The other day I was hit by a car, because I was deep in thoughts while I was crossing the road."*

Vigil and Clements (2003:35) too identified that reaction to grief may influence how the bereaved view the world in which they live as well as themselves within that world. This view can in turn complicate the grieving process, as a child's reaction to grief may include the following that were also exhibited by the respondents in this study:

- Absence of grief (dissociation that may result in showing no emotion)
- Unwillingness to speak about the deceased
- Expression of only positive or only negative feelings about the deceased
- New or increased acts of aggression and destructive outburst

- Feeling of persistent blame or guilt
- Experiencing anxiety and hypervigilance
- Prolonged dysfunction in school
- Assumption of parental roles and increased care-giving to adults and siblings
- Increased involvement in accidents (i.e. being accident prone)
- Engaging in stealing or other illegal acts
- Demonstrating signs of addictive behaviour

These reactions were explained thus by the respondents:

*"They say bad things about my father and in most cases you will find me fighting, because I don't like when they talk about him and his illness."*

*"Every time when there is something stolen in my neighbourhood, I am always a suspect. It happened that some of my friends stole the car and the owner came to my grandmother complaining that I stole his car. "(The expression on the clients face clearly showed guilt feeling as this was said with excessive fidgeting of the hands and respondent looking down)."*

*"On my way home, I would cross the roads without thinking, as I am asking myself as to what is happening to my mother at home while I am at school and some of my fellow students ask me whether I am sick. I am not performing well at school."*

*"I sometimes feel like joining some of the gangs at school."*

*"I am not doing well in class, and last year I couldn't pass, and so I had to repeat standard 4 for the second time...."*

### 3.9 NEED FOR CONTROL

Need for control is one of the significant motives for people's thoughts and behaviours. People need to feel they exert some control over their environment, and this has been identified to add some zest in their lives (Aronson, Wilson & Akert, 1997:24, 536).



As described by Pawlik and Rosenzweig (2000:458) and Myers (1998:445), a sense of control is an important aspect of personality in which individuals hold the firm belief that they possess the potential to execute the kinds of behaviours that a given task demands. This "can do" cognition mirrors a sense of control over one's environment. It reflects the belief of being able to master challenging demands by means of adaptive action. The control need was evident from some of the respondents with reference being made to doing things for themselves, as illustrated in Figure 3.4.

Table 3.6 illustrates the control needs as expressed by the respondents during the interviews. These needs have been quantified on the basis of the number of respondents who made reference to the same theme and in the same categories.

**TABLE 3.6:           Need for control of children affected by HIV/AIDS in order of their frequency (N=10)**

<b>NEEDS</b>	<b>FREQUENCY (F)</b>
Independence	
❖ Do things for ourselves	3
❖ Having own house	2
❖ Not telling people about our problems	2
❖ Not looking up to relatives	1
Family unity	
❖ Helping each other	3
❖ Living together	2
❖ Encouraging each other	2
❖ Struggling together	2

The control needs as described by the respondents will be discussed and their themes will be given as direct quotes.

### 3.9.1 Independence and family unity

According to Pearsall (2002:512, 720 &1568), independence means not depending on others for livelihood and subsistence, while family unity means a group of people related by blood or marriage. This group is self-contained and has a specified function.

The respondents in this study were aware of their situation, but their expression indicated that they wanted to be independent:

*"I asked her (the ill mother) to join an insurance policy, so she has got to pay that every month. You see, if anything can happen, I am not suppose to look up to our relatives and I don't want my mother to be always asking for help from the relatives, I think she has got to look after herself. I think we have got to struggle together with my mother as a family."*

*"We do not want the people around to know that we are struggling.....my mother wouldn't like to see us begging for food....."*

The researcher could not get hold of literature regarding the need to be independent concerning children affected by HIV/AIDS. The respondents were aware of their situation, but by means of their adaptive actions some of them seemed to master the challenging task:

*"Sometimes we would wait for people coming from town with a lot of grocery. We would ask then if we can help them carry the luggage from the bus stop to their homes and they would give us R10.00."*

*"Sometimes I would wash cars to get money."*

*"There are times when I think of leaving school and search for work. I wish I could do something for my sisters."*

These findings correlate with what Rotheram-Borus, Stein and Lin (2001:763) describe as coping-skills intervention among children affected by HIV/AIDS, whereby the children adjust to the impact of their parents' illness and death by assuming adult-like roles.

Besides showing some independence, the respondents in this study seemed to want to build a family unit. According to Gale group (2001:1), when people find themselves in trouble, they reach out and try their best to be together, i.e. blood is thicker than water. This was also exhibited by the respondents in this study:

*"Today is mother's day and it is also our mother's birthday. I hoped that we could have been with my other sister (half-sister staying with their stepfather), as they don't even know my mother's grave. I wished they had gone to the grave yard with us, but anyway, I will take them whenever they come back....."*

*"I am worried as to how my brother and sisters are feeling and what is going on in their minds and how our upbringing is going to be like....."*

*"We want to grow up together. The three of us together....."*

*"I wish I could do something for my sisters....."*

This was similar to what was said by Vigil and Clements (2003:30-38), that as a way of coping and adaptation during the process of grief, the surviving children/adolescents place a significant value on the maintenance of the family unit.

### **3.10 FIELD NOTES**

The researcher kept a written account of all the things heard, seen, experienced and thought in the course of collecting and reflecting on the data. This was for the purpose of remembering, retrieving, and for the analysis of data. Mayan (2001:14) maintains that without field notes, the data would be lost, and without the data, the analysis cannot proceed. These notes were submitted to the independent coder and consensus was reached for these to be included in a discussion of results.

## □ ***Observational notes***

Observational notes are descriptions of events experienced through watching and listening. They contain the what, where, how and who of a situation and contain as little interpretation as possible (Neuman, 1997:361; Wilson, 1993:222).

The home-based care workers were very familiar with all the residential areas of the respondents and they were welcomed into the homes as if they were relatives in these households. The roads in these communities where the respondents were staying ranged from gravel to tarred roads; however, there were lots of potholes. The houses were either four-roomed municipality houses or two-roomed RDP houses. There was no running water inside the houses, and as for other households, water supply was from the public taps. The houses were all electrified. The toilets were flush-toilets, except in two places where the bucket system was the only means.

The occupants in these houses ranged from three to eleven occupants. The school and health care facilities (MUCPP clinic as a catchment clinic) were within thirty minutes to one-hour walking distance for four respondents; as for others it was a two- to three-hour walking distance or a fifteen-minute drive by taxi. The heads of the households of the respondents ranged from being ill parents (3), grandparents (6) and a child who was also a respondent (1).

The home-based care workers were like part of the family in all the households and this assisted the researcher in being able to meet and be welcomed in the families. The appointments with the respondents were made through the caretakers and everything went according to arrangement, as the rapport had already been established with the caretaker.

There was no eye contact observed between the respondents and the caretaker. Communication between the caretaker and the respondents were of the one-way type: The respondents seemed very submissive to their caregivers. The respondents also did not make eye contact with the researcher, even though they were relaxed during the interviews. Some respondents showed reluctance to speak if the caretaker were in the next room and suspected to be listening to the discussion. Two respondents proposed to be interviewed away from the house and an arrangement was made to conduct the interview at the clinic. Some of the respondents cried during the interview, thereby delaying the interview and taking it off track.

The caregivers insisted that the researcher must not talk a lot about the deceased parents as this would trigger the respondent's' emotions. The other caretakers who were ill parents asked the researcher not to mention their HIV status to the respondents as they have not disclosed this to their children; however, the respondents seemed to have a suspicion based on gossip in the vicinity.

Two of the pre-orphaned respondents indicated that their parents were receiving sick-grants, while among the orphan's respondents, few were getting social grants, even though the respondents themselves were not aware of that, as this information was revealed to the researcher through the discussion with the caretakers. Other orphans had a birth certificate problem, as the parent never registered their births while still alive, while other orphans were in the process of being registered as South African citizens.

#### □ ***Inferential/ theoretical notes***

According to Neuman (1997:365) and Wilson (1989:435), these were purposeful attempts by the researcher, whereby she applied her own interpretation to infer or figure out what the observation meant, based on the knowledge of the cultural background, and clued from the context.

Continuous eye contact in an African culture is a sign of stubbornness; therefore the respondents avoided eye contact with the researcher as well as the caregiver. The respondents were reluctant to express themselves fully if they suspected that their caretaker could overhear them. This behaviour is based on the human element that they might be judged or treated by their caretaker based on what they had said.

It is a human element to be free when a third person without influence is ready to listen; hence the respondents were relaxed during the interview. Most black cultures avoid mentioning or talking about the deceased as this is thought to prolong mourning; one would not forget about the deceased. This explains the fact that the respondents didn't call their deceased parents by their names; 'she' and 'he' were used when referring to the dead parent. Some of the respondents (pre-orphans and orphans) cried when talking about their parents. Based on knowledge of the healthy grief process, the respondents seemed not to want to let go of the deceased or ill parent.

The pronoun "we" was mostly used by the respondents who had younger siblings. This provides a valuable insight into the culture of the household: *"I am not the only one affected"* and *"as a bigger brother or sister, I have to take care of others"*. It also shows interaction between the children within the household.

#### □ **Methodological notes**

According to Wilson (1993:222), methodological notes are instructions to oneself, critique of one's tactics, and a reminder about methodological approaches that might be fruitful. After being introduced by the home-based care worker, the researcher made her own arrangements with the caregiver with regard to the visits, as well as appointments made to meet the potential respondents. This self-involvement helped with building the rapport with the caregiver and it paved the way for contacting the potential respondents. When the researcher was introduced to the family for the first time, she was wearing a professional nurses' uniform. This initiated discussion between the caretaker and the researcher, as the caretaker's illness and concerns

about health were discussed and clarified, and in most cases some advice was given.

The researcher then decided to pay three visits to the homes before the interview. This helped the researcher to gain their trust and let them become used to her. This further showed the respondents as well as the caregiver how important this study was, which led to their commitment to the study.

Some of the non-verbal and verbal communication techniques were used for clarity of responses, verification as well as reflecting on what had been said. The researcher maintained eye contact with the respondent to show that she was attentive at all times and interested in what the respondents were saying. This benefited the study, as more information unfolded. The researcher focused the interview around the central question.

There were times when the researcher brought along some food packages to the household during the visits, as most of the time there was a complaint that there was absolutely nothing to eat. This was becoming a habit, and the researcher had to remind herself that she was only a researcher, and these little incentives could ultimately make it difficult for the researcher to leave the field when the time arrived.

As this was an interactive research, emotions were also evoked during the interviews; especially when sensitive issues like HIV/AIDS, illness and death of a loved one were discussed. When the emotions were stirred, the researcher waited for the respondents to gain control, instead of using the comforting acts of nursing, as at this stage the researcher was not there for the purpose of nursing. Instead, a suggestion was made to the respondents to see a counsellor, even though they turned down the offer.

## □ *Personal notes*

Personal notes are described as a researcher's personal reflections, reactions, emotions, mistakes and successes. These are a source of data about personal reactions. They give a researcher a way to evaluate observation or inference notes (Neuman, 1997:366; Wilson, 1993:223).

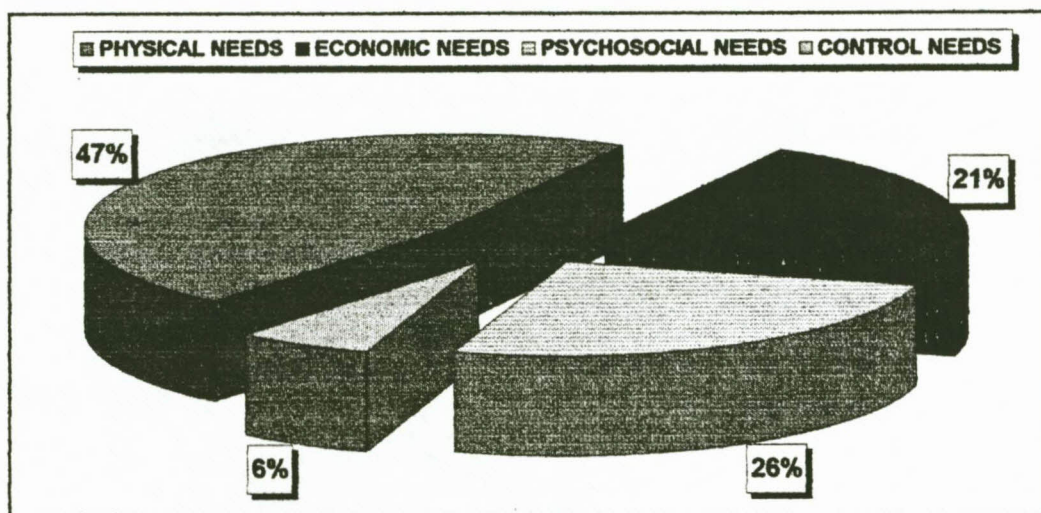
The researcher felt very much strained both mentally and financially, especially in houses where obtaining the next meal was a struggle to obtain. The researcher felt that the interview could not have succeeded if the respondents were hungry, and for this reason the researcher in most cases came with few loaves of bread and shared tea with the family before starting the interviews. The sharing of tea was for hospitality purposes.

The visits before the interviews were also physically tiring; as there were times that the researcher found herself helping the family with the care of an ill parent, and in a few cases even helping respondents with their school homework. Even though this was tiring, it helped the researcher to build strong bonds with the family as well as the respondents. This was good for the purpose of interviews, but it was a failure when the researcher had to leave the setting. Up to this stage the respondents as well as the caretakers are still contacting the researcher when they need help.



### 3.11 CONCLUSION

Orphans and pre-orphans have many needs as described in this chapter. It was clear that the psychosocial needs were really very important to them (Figure 3.5) as 47% of all responses focused on these specific needs. The second most mentioned needs (26%) were physical, followed by economic (21%) as well as needs regarding control (6%).



**FIGURE 3.5: Needs**

In this chapter, data presentation and literature control were discussed. A discussion of findings, study limitations, recommendations and conclusions will be dealt with in the next chapter.

## CHAPTER 4

### *Discussions, conclusions, recommendations and study limitations*

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#### 4.1 INTRODUCTION

The presentation of data and literature control were discussed in the previous chapter. In this chapter, discussion of the findings, conclusions, recommendations as well as study limitation will be presented.

#### 4.2 DISCUSSION OF FINDINGS

The findings of this study confirm that the children affected by HIV/AIDS, either as pre-orphans or orphans are extremely vulnerable, facing a myriad of problems that may have a lasting effect on their livelihood (the Joint United Nations Programme on HIV/AIDS, the United Nations Children's Fund, and the national Black leadership on AIDS 1999:1-3). With the illness and death of the parents, the respondents indicated that economic needs were the most prevalent (see Figure 3.2), and these paved the way for physical needs (see Figure 3.1). These needs were not isolated, as Wild (2001:13) also confirms; the economic and physical problems were being further complicated by the psychosocial problems. With these needs remaining unsatisfied, children are likely to be deprived of an opportunity and time to grow and develop successfully, hence their development is likely to be limited permanently with regard to the physical, emotional, social and intellectual aspect of development (Lyons, 1998:2).

The respondents indicated that their families as they were now could not fulfil their roles of providing a setting for nurturance and growth. As Murry and Zentner (1997:148) state, the physical and emotional needs of the family are met by parents providing their children with food, clothes and shelter, and promoting adaptation and adjustment. However, the children affected by HIV/AIDS in this study seemed deprived of this family function. The inability of the parents to provide the physical function could be attributed to the economic constraints surrounding these households. As Wekesa (2000:13) also confirms, AIDS drives more households into poverty or from poverty to destitution as a result of a decline in the household income, as parents stop earning their income, health care expenses increase, and funeral costs deplete all current and future reserves.

It was clear from the interviews that the respondents had to borrow money to pay for transport to take their parents to the health care services, while some of the respondents borrowed money to cover funeral expenses, actions that doubtlessly reduced the ability of these children to surf poverty. This was as described by Booyesen *et al.* (2002:13), that the use of the savings and borrowing of money appear to be common strategies for coping with illness and death; however, these pushed the household deeper into poverty as more resources are crowded out in favour of debt repayments in the absence of improved household income.

It is well known that the department of Social Welfare gives grants to people with terminal illness like HIV/AIDS, as well as to the orphans, including AIDS orphans (Policy Guidelines for Youth and Health, 2001:21-22). However, as the respondents in this study reported, these grants were always spent on the parent's medical expenses, hence nothing was really left for their needs. With regard to the orphan grants, few reported knowledge about them, and as for how the grants were spent only their caregivers could tell, while their needs continued to remain unsatisfied. Some of the orphans reported that they could not access these grants, as they did not have a birth certificate.

The problems of being unable to access the grants could be attributed to the fact that most of the respondents' parents were from the previously independent homelands like Transkei; the parents did not register the birth of their children at the time, and with increased modernization and urbanization, the families migrated to Mangaung (*this was discovered during the discussion with the caretakers*). On the death of the parents no one was available to start and finish the process of registering the birth.

The findings in this study further reveal that the current and the prevailing family structure of single-parenthood, with the head of those families being women, was one aspect that could have perpetuated the respondents' household's move from poverty to destitution. As reported by the HIV/AIDS affected children in this study, their mothers were the sole breadwinners, and with their illness, they had to stop working; upon their death, the debt increased as they (children) had to borrow money for their parents' traditional funeral. This single-parenthood family structure led to two most vulnerable family structures: the grandparent-headed households and the child-headed households, structures of which the circumstances are – as Ritcher (2001:32) comments – of mutual dependency.

Most respondents in this study reported to have received no physical or social support from their relatives (the uncle, aunts and nephews). This support (expected, but never fulfilled) from these particular relatives was considered a significant predictor of a supportive network for the respondents in this study. This African extended family structure as reported by Munodawafa (2002:8), was the one that was expected to take over when the children become orphaned. The brother, sister or the nephew of the deceased parent was supposed to have been the next parent.

In cases of illness, the affected family usually relies on, and is dependant on the kin group for psychosocial and physical support according to the traditional African norms (Mundawa fa (2002:8). However, this supportive network was just a history on paper for the respondents in this study, as they had to nurse their parents until death and at the same time fend for themselves and their siblings. This was also confirmed by UNAIDS (1999:5), that this social safety net had not proved as resilient, as those expected to provide care were already impoverished.

Lack of support from close relatives during the illness and death of parents was shown to be one of the critical concerns for the respondents in this study. The fact that the respondents could not adjust and adapt to their situation proved that they expected some form of arrangement with regard to their guardianship. As Murry and Zentner (1997:791) indicate, a person normally plans ahead religiously, philosophically, financially, socially and emotionally if his/her death was not sudden or unexpected, and if the person is aware of the prognosis of the illness.

The parents of the respondents in this study were aware of the prognosis of their illness, but there were no arrangements at hand for the guardianship of their children. This lack of planning, or the reluctance to initiate such planning may be attributed to the concern about imposing a burden on the potential guardian as well as reluctance to face one's potential death (Wilfert *et al.*<sup>7</sup>, (1999:509-510). However, the other reason could be that the parents too were aware of the fading extended family support structure.

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<sup>7</sup> Aronson, Beck, Fleischman, Kline, Mofenson, Scott, Wara, and Whitely-Williams( A team of medical doctors on pediatric AIDS)

The failure to discuss the children's guardianship was also confirmed by Niebuhr, Hughes and Pollard (1994:421-425), in which the parents in their study did not seek help, probably for fear of asking for help and not finding it. Furthermore, the parents were worried about the distrust and social anxieties that normally prevail within social networks of the families. Gilborn *et al.* (2001:13-15) also identified that the parents do believe in the need to make explicit arrangements for the guardianship of their children, but could not carry out the plan because they did not wish to reveal their HIV status. To other parents, the reluctance was due to the fact that the person to be appointed was also ill, old or even HIV-positive.

Furthermore, the findings revealed that the parents did not discuss (in the case of orphans) or did not want to discuss (in the case of the pre-orphans) their illness with their children (during the visits, the researcher was told by the parents/caretaker not to mention the diagnosis to the children). Probably this was done to protect the children from the fear of potential loss, as well as from the stigma surrounding their illness. This phenomenon was also identified by Niebuhr *et al.* (1994:421-425). Their assumptions were that parents were embarrassed and unable to admit to the children their own behaviours which led to HIV infection, but unaware of the child's concerns related to the parent's illness; these assumptions could be prevalent in this study.

The findings in this study further revealed that the respondents' schooling was interrupted, as there were times when they were suspended from school because of lack of school fees or incomplete school uniforms. Ritcher (2001:32), Gilborn *et al.* (2001:18), United Nations Educational Scientific and Cultural Organization (UNESCO) and UNICEF (1999:1-2) as well as Ayieko (1998:9-10) confirm that school attendance of children become interrupted in households affected by HIV/AIDS. Their conclusion with regard to this problem pointed to expensive school fees, too many unaffordable school requirements, as well as the children having to provide labour in their homes to compensate for adult illness in the family. However, their assumption went further to the fact that other children may stay away from school owing to embarrassment and fear of being stigmatized as an AIDS orphan or pre-

orphan, or owing to lack of parental guidance and encouragement. Some of their assumptions could be applicable to some of the pre-orphans or orphans in this study.

Respondents in this study reported that school policies were rigid, as they were not allowed to come to school if school fees remained unpaid. In some cases the academic progress reports were held back at school, despite the fact that the school fees would ultimately be paid. According to the respondents, this had an impact on their education, as their education was repeatedly interrupted. As reported during the interviews, the respondents saw their future in the light of their education. They seemed to rely on education for a better future. Higgs (2000:5) and Gorga (1999:2-3) justify their concern by saying that the child with poor education will have no incentive in the economic world, because access to economic stability is based on the acquisition of specialized knowledge.

Most of the respondents in this study indicated that they sometimes had to work at unskilled jobs like washing cars, cleaning gardens for other people, in order to earn some money for their education. Some respondents indicated that they sometimes felt like leaving school, while some were even advised by their friends to leave school. Besides all these pressures, the respondents indicated that they did not consider jeopardizing their meagre opportunity for education and become permanent breadwinners. They were all clearly aware that schooling or education was their only escape from poverty.

The respondents in this study had also reported lack of understanding by the community as well as rejection based on the illness of the parents. These findings are not reassuring, as community support is one of the social networks, and a most comforting one if the extended family structure is not delivering. This confirms Ayieko's (1998:17) finding that the devotion and attachment in the community is fading, probably because of the discouraging number of HIV/AIDS deaths. This fading community attachment may be attributed to the stigma associated with HIV/AIDS. Among other problems related to the fading of this previously trusted social network, Kerkhoven

(1998:4-5) indicated that there are social and economic problems that have weakened the capacity of the communities to respond to the plight of children affected by HIV/AIDS.

The majority of the respondents in this study reported their desire to establish social bonds with other children at school as well as in their neighbourhoods. This heightened the importance of friends or friendship during this period of their lives (11 to 18 years of age). As the findings revealed, this was impossible, as they had no time to be with other children. As UNAIDS (1999:5) too indicated, the children affected by HIV/AIDS are faced with added household responsibilities that bring on stress that would exhaust even the adults. The respondents in this study agreed with Lyons (1998:5) that they do work long hours doing household work, school tasks, supervising siblings as well as engaging in income-generating jobs. However, at some stage these added responsibilities brought about the feelings of wanting to quit where providing for the ill parent wasn't possible or when the child was unable to cope.

The other factor that was of concern regarding establishment of social relationships was rejection by friends. This created a stressful situation, because the respondents felt that they would have loved to spend the little free time they had with friends, but all that they received was rejection. As some of the respondents reported, this was due to the stigma surrounding HIV/AIDS. However, Zerwekh (200:47-60) indicates that besides being rejected, children too may isolate themselves because of fear and embarrassment, and this might have been the reason in this study. UNAIDS (1999:5) confirm this by saying that children do experience distress, social isolation both before and after the death of their parents, and these are strongly exacerbated by shame and fear. This may deny many children their rights, and furthermore, it can affect their self-esteem, as was the case in this study.



Inability to cope with the illness and death of the parents were other findings in this study, and this revealed the need for counselling. The fact that the mentioning of the parent's name still triggered painful emotions, and that some of the respondents' caretakers indicated to the researcher beforehand, that the name of the parent must not be mentioned, and that the discussion must not dwell unnecessarily on the deceased parent, indicated that the respondents who lost their parents had still not come to terms with the reality that they have lost a parent.

Some of the respondents indicated that they have forgotten about their deceased parents, but the mentioning of their parents' name triggered their emotion and they even admitted their loneliness. These findings reflected the findings of Van Epps, Opie and Goodwin (1997:30-31) in which youngsters were severely reprimanded for asking questions about the deceased. These findings confirm the researcher's cultural orientation regarding death, grief/mourning within the African belief system.

The researcher, being a black African, is aware and part of the African belief system, whereby under-aged children<sup>8</sup> are supposed to be protected from pain of loss. This protection normally starts from when it is realised that a parent is terminally ill. At this stage the children are not encouraged to be with the dying person, in case they would realise the potential death of the loved one. This, however, led to children being unprepared for the actual death of their parent.

With the actual death, there is customarily a renaming of the deceased, in which reference to his/her name is replaced by a universal name "Mofu" (the deceased). Once renamed, reference to the dead person's real name actually diminishes, and this is a way of showing and telling the bereaved that their beloved is no longer part of them. The deceased is now part of the ancestors (Balimo). This whole process is partially meant to shorten the mourning process. Besides renaming of the deceased, the belongings of the deceased

are normally distributed among the relatives, so that the mourners may forget quickly and also have nothing to remind them of the deceased. This is intended to reduce the mourning process (this is based on the practices of the black Africans, and like most of their norms and values it is not documented).

Furthermore, the results of the study revealed that the respondents showed a need for information, as they could not accept or believe that their parents were suffering from or had died because of AIDS. Their denial could be attributed to the fact that their parent did not confirm their suspicion as brought about by the gossip and the actual appearance of the parents. The issue of parents failing to tell their children about their HIV status was explored by Niebuhr *et al.* (1994:421-425). Their findings reveal that this was related to the parents' fear of discrimination against the children. However, the parents were not aware of the children's emotions related to the parents' illness, as was the case in this study.

As described by Rotheram-Borus *et al.* (2001:768-771), parents and children form an interdependent and interactive social unit; when parents become infected by HIV, the entire family is affected, hence the zest for information to confirm the suspicion. Nevertheless, the respondents in this study did not want to believe that such a disease could infect their parents. Having heard about the stigmatized mode of HIV transmission, the respondents could not allow themselves to accept that the same way of transmission happened with their parents. Niebuhr *et al.* (1994:424) assumption was also related to this, as in their findings, the parents too were embarrassed to admit to the children their own behaviours which led to the HIV infection.

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<sup>8</sup> Childhood in African cultures ends with marriage. That is if the child is 24 years and unmarried, is still considered to be under age.

As Abrams (200:15-16) and Hodgkinson and Stewart (1998:140-141) admit, giving of information, and not omitting to give children clear and honest information is vitally important, and set the agenda for recovery. However, this was not the case in this study, as the respondents learned about their parent's illness in a hushed way through gossip, which gave rise to a lot of anger, as some of the respondents experienced the stigma of their parents' illness without the parents disclosing their diagnosis.

The findings of this study further indicated that the respondents expressed their willingness to be independent as a family unit. They explicated the desire not to be separated, but to struggle together. The findings of Rotheram-Borus *et al.* (2001:764) also confirmed that adjustment to death or illness of a parent because of HIV/AIDS is exemplified by children assuming adult roles and older ones taking more responsibilities. As Vigil and Clements (2003:34) also confirm, the grieving children place a significant value on the maintenance of the family unit when coping and adapting to the loss. This was also reflected by the respondents in this study.

### **4.3 CONCLUSIONS**

Ten individual unstructured interviews were conducted with the children affected by HIV/AIDS, either as pre-orphans or orphans. The respondents were between the ages of 11 and 18 years. Six of the respondents were males while four were females.

The findings of the study confirmed that the terminal illness and the ultimate death of a parent because of HIV/AIDS placed the surviving children in an extremely vulnerable position, with a myriad of problems. With the breadwinner being ill or deceased, children found themselves being without food, clothes as well as being suspended from school from time to time on account of unpaid school fees and other school-related issues. The study revealed that grant relief for these children both as pre-orphans and orphans

is necessary, but this needs proper coordination to ensure that these really help the affected children.

These physical and economic needs were not isolated, as the illness further exposed them to psychosocial problems. Besides being discriminated against by the community around them, the study revealed that the relatives, the very same people that are trusted to look after them, distanced themselves and denied the affected children support. With added responsibilities such as nursing their parents, providing for, and supervising their siblings, these children were faced with a social life without friends, who at times discriminated against them. This also added to their lowered self-esteem.

However, what was encouraging was the fact that their sense of control over their environment was explicit. They did not learn helplessness as if the outside forces or chances determined their fate. Their efforts to survive were based on small-scale methods of generating money, coupled with limited skills involved. This gives an indication for proper skill analysis and development for children affected by HIV/AIDS.

#### **4.4 RECOMMENDATIONS**

It is clear from the discussion of the findings and conclusions that, children affected by HI/AIDS either as pre-orphans or orphans have various or diverse needs, that mostly cluster around the physical, economic and psychosocial aspects, and also a need for a sense of control over their environment. Based on these, it would be advisable that the services that help these children become aware of their needs and provide support, and where possible, with these children as active participants.

#### **4.4.1 School programmes**

The findings of this study revealed that provision of food was unmet as the parents were either dead or too ill to generate income for provision of food, as well as provision of school necessities such as school fees, school tours and stationery, and for this reason it would be advisable for schools to redesign programmes that will benefit not only the affected children but also other needy children attending school, thereby limiting the HIV/AIDS stigma. At this juncture it would be advisable if the Departments of Education, Social Welfare and Health, as well as non-governmental organizations could join hands in the establishment of such programmes. The report of this study will be disseminated for this purpose.

##### **4.4.1.1 School feeding programme**

The most important suggestion is the initiation of school feeding programmes, aimed at enhancing attention span and learning capacity of learners by relieving the short-term hunger. These programmes already exist, but they are limited to a few schools. It is essential that they be extended to other schools as an incentive for all the poor and hungry children at school, and not only those affected by HIV/AIDS, as there could be stigma attached to this commodity programme.

Once these feeding programmes become established, they can be expanded to include breakfast programmes, accommodating children who come to school without having had a meal. At this juncture, the local food companies like bakeries and dairies could be encouraged to make a contribution by offering a certain amount of their products to schools, based on the strategies that will be developed to classify schools as being needy schools.

Furthermore, these programmes may be evaluated annually so as to increase coverage of potential beneficiaries, and also to determine the schools' need for food, based on extrapolated information.

#### **4.4.1.2      *School-based vegetable gardening programme***

The school vegetable gardens have already been established by the first year nursing students of the University of the Free State in some of the schools in the Free State. However, this is limited to a few schools, hence it is advisable that the Department of Education and Health join forces in establishing such a programme in all schools in the Free State.

Introduction of vegetable gardening in schools should be directed to delightful outdoor recreation rather than part of the school curriculum. Vegetable gardening can address many hardships for all poor children at school, not only those affected by HIV/AIDS:

- Vegetables cultivated in these grounds could be used as part of the feeding programmes, hence relieving hunger. The findings in this study indicate that all the respondents' complained of hunger during school hours. Eaten fresh, the vegetables would also give extra protection to children, who because of poverty do not always have access to food with micronutrients.
- These programmes could also be of great economic value, as the vegetables could be sold, and the resources gained could be utilised to satisfy the children's various needs: for example, payments of school fees, buying of the stationery, as well as catering for scheduled school trips for the needy children, based on the active involvement of these children in the projects.
- Another benefit of gardening is teaching children to realise how quiet, slow and thorough the processes of nature are, as compared to our modern, hurried, impatient lifestyle. As Agar and Dove (1909:iii) comment, gardening can further teach children that human beings are not only trained by nature, but they can rise above nature and even

assist nature to attain higher development than could be secured without the cooperation of man's intelligence. With this in mind, it could be a healing process with regard to the impact of the illness and death of their parents.

#### **4.4.2 Coordination and control of the social grant programme**

Financial assistance in the form of social grants is important for ensuring the care of orphans; however, there are some loopholes with regard to the policy in this regard. Therefore it would be advisable to revise the policy guarding this programme, with much emphasis on the following:

- Considering the pre-orphans in getting these grants as well, as the findings of this study indicate that the social grants received by their parents were being used to cover medical expenses. With the current rolling out of treatment for people infected by HIV/AIDS, it would be considerate to cut the financial assistance to the parents and initiate grants for pre-orphans. This could serve to ease their hardships as well.
- Initiation of policy stipulating what should happen if the beneficiaries did not benefit from these social grants as intended. This is based on the findings of this study, namely that even those children receiving grants were still experiencing the same problems experienced by those who had not yet received grants. This then raises concern as to whether the children really do benefit, or whether it is only the caregivers who benefit. Besides the clauses that need to be included in this policy, there must be a follow-up system to evaluate its usage, as well as the well-being of the beneficiaries.

- Another suggestion is the empowering of the communities with regard to the social grant policies, and monitoring of vulnerable households, aimed at establishing a system for identification of such families. The community must also be empowered regarding their roles in the support of the beneficiaries as well as the channels they as community members are to follow if the grants did not benefit the beneficiaries. This would be the initial phase of re-enforcing the community values that should be given priority with regard to the care of children affected by HIV/AIDS.

A report on this issue will also be disseminated to the Department of Social Welfare, as a proposal for the restructuring of the policies that guide social grants.

#### **4.4.3 Counselling programme**

In the context of HIV/AIDS, it is undeniably true that the parents suffering and dying from HIV/AIDS will in the course of their illness be in contact with health professionals, particularly nurses. It is at this juncture that nurses in their particular sphere could initiate counselling services for the surviving children, so as to enable them to cope with the illness and ultimate loss of their parents.

Many studies have identified that children from households stricken by HIV/AIDS become affected long before the death of the parents, since there are long periods of uncertainty and intermittent crises as parents slowly sicken and die (UNAIDS, 1999:4-5). As identified by Gilborn *et al.* (2001:21), and also as in the case of the respondents in this study, the affected children experience worry, loneliness, as well as denial and ignorance about the nature of the parent illness and death. Furthermore, the previously trusted traditional method of psychological support (kinship) has long since proved itself resilient. It is therefore imperative to reshape and improve the



professional counselling programme available to meet the needs of children affected by HIV/AIDS.

It should be clear that counselling programmes already exist in the Free State; however, these seem to be catering for voluntary counselling and testing (VCT). Much emphasis is placed only those who want to know their HIV status, but as for those affected by HIV/AIDS, counselling services are non-existent or otherwise unutilised. The report of this study will be disseminated to the Department of Health as well as the institutions that train counsellors. The counselling programmes are therefore proposed to incorporate the following:

- Services to help the parents to disclose their HIV status to their children, as most of the respondents only had a suspicion or heard gossip about their parents' HIV status. This seemed to cause the respondents in this study considerable distress. In dealing with this, the respondents could not confront their parents; instead they chose to ignore or deny the fact that their parents were infected by HIV/AIDS.
- Services to help parents to plan for their children. This should include the identification of a valuable source of support from the list of their relatives and friends, and subsequently to the appointment of guardians. This is to reduce the children's anxiety and ensure future care for the children. As the impact of parental illness was one aspect that caused distress as well as added responsibilities that the respondents were unable to cope with, the identified guardians could also assist in caring for an ill parent.
- This counselling and support to children affected by HIV/AIDS must be ongoing services. As it started with the parents' disclosure of their HIV status to their children, it should extend to preparing children for the death of their parents up to the stage of bereavement. As the children

would then be familiar or used to the person offering the service, it would be easier for them to access the service if problems arise.

- These services should incorporate outreach programmes aimed at counselling. Outreach work involves taking services to where the target population congregate in large numbers. In dealing with children aged 11 to 18 years old, schools are appropriate places for counselling. Thus it is suggested that school counselling programmes be established as an outreach initiative. This would involve training of skills and strategies for teachers, and the involvement of students doing counselling psychology, as well as school health nurses in such services would be of utmost importance. It is at this juncture where children with problems could be identified and referred to appropriate services such as social grants or foster care. These outreach services could also incorporate community members as a further support to the outreach programmes.

Counselling programmes should always consider the following:

- Cultural and traditional issues
- Religious issues
- Gender issues
- The age of the child.

#### **4.4.4 Further research**

It is worth noting that the study was conducted only on subjects whose parents were under Hospice's programme of home-based care, and that the sample was a convenient sample. It is also important to note that the study only included Black people in Mangaung, as the researcher would have found it difficult to conduct interviews in Afrikaans if Coloured and Afrikaner communities had been included. The researcher therefore recommends that research be conducted on:

- The other races, as this would give a broader picture of the needs of children affected by HIV/AIDS.
- The coping strategies used by children affected by HIV/AIDS.

#### **4.5 LIMITATIONS OF THE STUDY**

- The researcher conveniently identified the respondents in this study, and that other races were excluded in this study. Hence many potential respondents were excluded, possibly with diverse needs from different cultures.
- Translation of tape-recorded interviews from the different languages to English may have resulted in loss of information. The researcher is not Xhosa by birth, and for this reason, a colleague who is a Xhosa by birth was consulted to verify the translation, hence correct translation into English was ensured. As for the Tswana and Sotho, there was no problem, as the researcher is fluent in both these languages.

#### **4.6 CONCLUSION**

The purpose of this study was to identify the needs of children affected by HIV/AIDS. An explorative, descriptive and contextual design within a qualitative paradigm was used to reach the purpose of the study, and based on the results, it may be safely concluded that the purpose of the study has been achieved. Recommendations have also been made to the appropriate bodies, and the report of this study will be disseminated to them.

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***ANNEXURE A***

***Director of Naledi Hospice: Request for  
permission***

P.O Box 6840  
BLOEMFONTEIN  
9300

4 March 2002

The Director  
Institute  
BLOEMFONTEIN

Dear sir/madam

**RE: REQUEST FOR PERMISSION TO CONDUCT A STUDY**

I am currently pursuing my master's degree in nursing science at the University of the Free State.

May I kindly request a permission to conduct a study in your institution, and where applicable to refer me to the older siblings of children under your care. The study is on the needs of children affected by HIV/AIDS. This study will be conducted in fulfillment of the above-mentioned degree.

The results of the study will not benefit the children directly, but it will provide information for the improvements of the public services and the programs that assist these children, and may determine the nature of services that are likely to be required for these children, in the light of promoting child participation in democratic decision making.

A copy of the research proposal will be sent to you for review as soon as it has been approved by the Ethics committee of the faculty of Health sciences of the University of the Free State

Your usual co-operation and assistance will be appreciated.

Yours faithfully

---

**Rosemary M. Mpeli**

**ANNEXURE B**

***Ethics committee approval letter***

# UNIVERSITY OF THE FREE STATE



## Office of the Director: Administration Faculty of Health Sciences

339 BLOEMFONTEIN 9300

(051) 405-3013 / 401-2847

Enquiries

Mrs G Niemand

REPUBLIC OF SOUTH AFRICA

TELEFAX (051) 444-3103 SA

Tel 4053004

19<sup>th</sup> February 2002

MS RM MPELI  
C/o DR L ROETS  
SCHOOL OF NURSING  
UNIVERSITY OF THE FREE STATE

Dear Ms Mpeli

**ETOVS NR 33/02**

**RESEARCHER: MS RM MPELI**

**PROJECT TITLE: NEEDS OF CHILDREN AFFECTED BY HIV-AIDS: MANGAUNG IN THE FREE STATE.**

You are hereby informed that during their meeting held on the 19<sup>th</sup> February 2002 the Ethics Committee approved the abovementioned protocol.

Your attention is kindly drawn to the following:

- a) A progress report be presented not later than one year after approval of the project
- b) That all extensions, amendments, serious adverse events, termination of a study etc have to be reported to the Ethics Committee

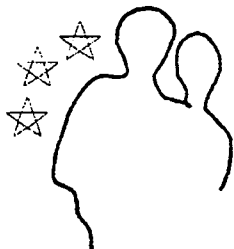
Will you please quote the Etovs number as indicated above in subsequent correspondence, reports and enquiries.

Yours faithfully

**For DIRECTOR: MEDICINE ADMINISTRATION**

**ANNEXURE C**

***Approval letter from the Director Naledi***



# Naledi Hospice

(Formerly Bloemfontein Hospice)

A Member of the Hospice Association of South Africa

P.O. Box 28391  
Danhof  
9310  
Tel.: 051 - 4477281  
051 - 4304846  
051 - 4478208  
Fax: 051 - 4477358

5th March 2002

Ms. R.M. Mpeli  
P.O.Box 6840  
Bloemfontein  
9300

Dear Rosemary,

Re: Request for permission to conduct a study.

Your request to do a study has been granted.  
Please could you let us know the dates you will be  
visiting so we can tell the Sister-in-Charge.  
Or you can contact Sr. Emma Belot on 448 3812.

Yours Truly,

or contact me 082 296 4367.

Sr. J. Marston  
Executive Director

***ANNEXURE D***

***Consent form***



# **CONSENT FORM**

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**STUDY TITLE:** Needs of children affected by HIV/AIDS:  
Mangaung in the Free State

**RESEARCHER:** R. M. Mpelé (M. SOC. SC Nursing student)

I am a student at the university of the of the Free State and I am doing a study on the needs of children affected by HIV/AIDS, in order to give recommendation to the public service providers and the programs that assist these children. Although this study will not benefit the children directly, it will provide information for the improvement of public services and will also determine the nature of services that are likely to be required.

If you as caretaker agree to let the child participate in this study OR you as a child agree to participate in this study, an interview will be conducted by a child psychiatry specialist who will be accompanied by the researcher. The interview will take about 30 minutes and may be followed by subsequent short interviews for clarification. The interviews will be audiotaped for analysis by the researcher and to verify findings through independent expert.

The study procedure involves no foreseeable risks or harm to the child or the family, as it only involves responding to the questions on the needs of the child.

Participation in this study is voluntary and the child has the right to withdraw at any time. The child identity will not revealed while the study is being conducted or when the published. No unauthorized persons will have access to the collected data

I have read this consent form and I voluntarily agree to participate or let the child participate in this study.

_____	_____	_____	_____	_____
Caretaker's signature	Date	Subject's signature	Date	Relationship to the subject

I have explained this study to the above caretaker and the subject and have sought their understanding for informed consent: .....

_____	_____
Researcher's signature	Date

***ANNEXURE E***  
***Protocol for data analysis***

# *PROTOCOL FOR DATA ANALYSIS*

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- Get a sense of the whole. Read through all of the transcriptions carefully. Write down the ideas as they come to mind.
- Pick one most interesting interview; go through it, asking yourself: what is this interview about? Do not think about the substance of the information, but rather on its underlying meaning. Write thoughts in the margin.
- After you have completed this task with other interviews, make a list of all topics. Cluster similar topics together. Form these topics into columns that might be arrayed as major topics, unique topics and leftovers.
- Now take this list and go back to your data. Abbreviate the topics as codes and write the codes next to the appropriate segment of the text.
- Find the most descriptive wording for your topics and turn them into categories. To reduce the total list of categories, group together the topics that relate to one another. Lines may be drawn between the categories to show interrelationships.
- Make a final decision on the abbreviation for each category and arrange these codes alphabetically.
- The data materials belonging to each category can then be assembled in one place, and a preliminary analysis can be performed
- If necessary recording of the existing data will be done

***ANNEXURE F***

***Transcription of interview no. 2***

# TRANSCRIPTION OF AN INTERVIEW

NO 2:08/04/2003

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**Researcher:** *"Today I have come per our appointment, as I have indicated that we are going to discuss something with you."*

**Subject no-2:** *"Ok."*

**Researcher:** *"I would like you to please tell me all about the problems you are encountering since the illness of your mother."*

**Subject no-2:** *"Mm... There are lots of problems in this house since my mother's illness. I am no longer getting clothes like before. That time when she was not ill, she used to go out and get some piece jobs. That is why she was able to buy anything that I would need. "*

**Researcher:** *"Mm."*

**Subject no-2:** *" ... there are times in this house when you will find that there is no food, because there is no money."*

**Researcher:** *"Uh."*

**Subject no-2:** *"... I am not even attending school well because there is no one helping with the payment of the school fees. At least with the little money she used to earn, she used to settle my school fees and other things needed at school and other things at home and those that I personally need."*

**Researcher:** "Uh."

**Subject no-2:** *"And the other problem I now have is, I can't concentrate well while I am at school ... (silence) ... I know I am her only child. And now and then I have got to think about her too, as to whether she has eaten, whether she did get water to wash herself, and whether she has received the other things she is supposed to get at that time; like medicine. Especially because she is now and then giving some problems, I cannot concentrate while I am in class."*

**Researcher:** *"Can you explain what you mean by "she is now and then giving some problems?"*

**Subject no-2:** *"She is giving some problems now and then because you will find that I will leave for school in the morning and when I come from school at break to come and eat, I will find that she is terribly ill again, she is vomiting a lot ... this disease I am really not to be in the house, I would prefer to spend most of my time with friends ... sometimes on Fridays, Saturdays, and even on Mondays when I come back from school I would take off my uniform, and sometimes I wouldn't even eat, and I would go outside. I really don't want to be in that room where she is lying, because I am scared of the disease she is suffering from."*

**Researcher:** *"What do you mean by being scared?"*

**Subject no-2:** *"I am scared that I might be infected too."*

**Researcher:** "Uh."

**Subject no-2:** *"Especially because she is coughing a lot, and if ... I think if I am always close by or sitting next to her I might be infected ... there are no ... I don't know how to explain this. There are no separate dishes and other things. .... Because they normally say a person with TB is supposed to use her own dishes and cutlery. And everything that she uses must be used by her alone. We are not supposed to use the things that she is using, but we are sharing things in this house. That is why I think I have been infected by this disease. Already the past three weeks I have been coughing terribly. I think she has already infected me ..."* (Silence)

**Researcher:** *"Uh."*

**Subject no-2:** (Silence)

**Researcher:** *"Please describe to me your other problems?"*

**Subject no-2:** *"The other thing is the envy I have for other children's possessions. Other children have got cell phones and a lot of things. And when there are school trips, other children are able to go, and I cannot go because there won't be anybody to pay the fares for me .... I am unable to be at the standard of other children, since the illness of my mother. That is why sometimes I feel uncomfortable to be with friends."*

**Researcher:** *"Uh."*



**Subject no-2:** (Silence). "... The other problem: I don't have money. There are days that you will find that there is no food in the house. And because I don't have money I will spend the whole day at school without food. We spend a lot of hours at school, and you will find other children eating, and I won't be eating for the whole day. And that is why sometimes I envy other children's things. Sometimes I even say to myself I wish that my friend's mother could be my mother, because of the problems in the house."

**Researcher:** "Uh."

**Subject no-2:** "These people in the house are always scolding me and I don't like it. I don't feel comfortable any more in this house. Sometimes, even if I feel like helping around, I always feel discouraged; I don't know what could be the problem. Sometimes I would feel sad and I would pack my bags and tell them that I am leaving. But then I would say to myself; whatever I am planning is not good, because I might also get this disease ..." (Silence)

**Researcher:** "Uh."

**Subject no-2:** "The other problem is, I don't have school shoes, and I cannot imagine myself going to school kaalvoet (bare-footed). The other thing is, at school they want us to have a complete uniform. And since it is winter now, they will want us to have winter attire too, which I don't have, and that is why I decided not to go to school. I haven't been to school since the last two weeks before the school closed up to today, because I know they will want us to have ties on, and sweaters and shoes, as well as sport shoes, all of which I don't have. The other thing I would like to do is singing in the school choir, because I do have that talent,

*but since I have been to this school I am no longer interested in singing, because if I see the other children next to me with some things I really need, I become very jealous and sometimes I would have bad feelings, as if I could do something bad to that child because of what he has."*

**Researcher:** *"Uh."*

**Subject no-2:** *"And sometimes I feel like joining some gangs at school, but my conscience cannot allow me to join ..."*

**Researcher:** *"Can you explain more about that?"*

**Subject no-2:** *"There are these gangs ... In fact I can say there are groups at school. There are groups for dagga smokers, those who drink alcohol and those who smoke cigarettes. So sometimes I feel like joining one group, because you will find that during break time, the group members sit and chat together, and sometimes if I have R5.00, these guys belonging to a certain gang will take that money by force in order to buy either dagga, alcohol or cigarettes for other group members. And if my money is taken, I would just look at them because there is nothing that I can do. There are no strict measures taken even if we report the incidents to the teacher. You know, one cannot fight at school because one would be expelled from school. After they took the money I would have nothing to eat, as this was the only money to buy food with during break ..." Silence).*

**Researcher:** *"Uh."*

**Subject no-2:** *"That is why I sometimes feel like joining these gangs."*

**Researcher:** "Uh."

**Subject no-2:** *"The other problems are ... I am unable to...I am never happy at school. When other school children are happy I always feel very sad...that is why I would prefer if my mother were not around. Sometimes I do ask God as to why He (God) is not taking her because she is really suffering. That is why I want to stop attending school. The other thing is that I really don't want to stay with a sick person like this in the house because I am really scared..."*

**Researcher:** "Uh."

**Subject no-2:** *"The other thing is the church. I am supposed to be paying the monthly thanksgiving-offerings at church for myself and also for my mother, but where will I get the money for that? Because there is no money, and there is nothing in the house. I don't have clothes. I have nothing to wear to church or during the weekends so that I can also look nice. And I really don't like all these things."*

**Researcher:** "Uh."

**Subject no-2:** *"We have got other families; my uncles. They don't even think about me when they enter the clothing shops. They don't even buy a T-shirt or something for their sister's child. They do totally nothing for us. They don't even come to see us, even if I phone them to come and see my mother, especially when she is seriously ill. They won't come. They would stay at their homes because my mother's illness is not their problem. It is my problem ..."*  
(Silence)

**Researcher:** "Uh."

**Subject no-2:** *"You know, they are really brother and sister by blood, but they don't like each other. And the reason for all this is my grandmother's pension grants. My uncles believe that my mother, being the last born in their family has been using that money to raise me."*

**Researcher:** "Uh."

**Subject no-2:** *"My cousins are working too. But it is very difficult for them to help me because sometimes even if they want to buy me something, their fathers (my uncles) stop them by saying that I have my own mother who is supposed to buy everything for me. They said she must leave the bed and go for piece jobs, as she used to claim that she got her money from piece jobs. They said we like to show off especially if we have beautiful things. Because of that they say they can't help us. And for that matter, I am not the kind of a person who likes to hang around the street corners to show off whatever I have. Yes, I do want to be with people. I like being with friends, and there is only one friend that I always hang out with, or I go to his place. But anyway, I will make peace with that as time passes ..."*

**Researcher:** "Uh."

**Subject no-2:** *"I no longer have money like before, especially during Fridays. You know, during Fridays, at that time when my mother used to come home with some money from her wages, I used to have money to buy nice things with my friends. But now it is different. Even when my friends ask me to go out with them, promising to buy or to pay for me, I don't feel comfortable even if I sometimes do go ..."*

**Researcher:** *"Uh."*

**Subject no-2:** *"I don't feel free, because I have left a sick person at home. We are only three in this house, and my grandmother is blind. That is why I prefer to be with them in the house, or if I am with friends, to come home now and then, so that if there are some problems I am readily available. I don't go far away from home in this area, because I am now experiencing bad things ..."*

**Researcher:** *"Can you explain that?"*

**Subject no-2:** *"They nearly stabbed me with a knife ..."*

**Researcher:** *"Mm."*

**Subject no-2:** *"This past Saturday I was coming from the shops and they nearly stabbed me with a knife. They said I am neglecting them; I am no longer spending nice time with them. I think it is because I no longer give them money like I used to. If I had money I used to share it with them as friends. They did ask for money and then they said I am always in the house with my sick mother. And I didn't like it when they talked about her illness."*

**Researcher:** *"Mm."*

- Subject no-2:** *"They also said I too have that disease she is suffering from. Sometimes even other children avoid me. If I start playing with them, they would walk away saying that I might infect them with my mother's illness. They say we all have this illness in the house, and that I am going to spread it all over this neighbourhood. But there are some who do understand, who will say; "How sure are you that this guy is also infected? Take it easy gents." There are some who still point fingers behind my back asking if I am not sick too. Sometimes when I pass by they start talking, saying that my mother have such and such illness. But even me too, I don't know if HIV can infect one just like that: say by staying in the same house with my mother."*
- Researcher:** *"Uh."*
- Subject no-2:** *(Silence)*
- Researcher:** *"Any other problem?"*
- Subject no-2:** *"That is all about my problem."*
- Researcher:** *"Ok .... I would like to thank for your time and the information you have provided. Thank you."*
- Subject no-2:** *"I am the one who should be thankful ..."*

