CHAPTER 1: ORIENTATION

1.1. INTRODUCTION

In this chapter a preview is given about the research conducted on the perceived psycho-educational needs of children orphaned by AIDS* who are being cared for at two care centres situated in the rural areas of KwaZulu-Natal. (*In order to avoid tedious repetition of this term, the term AIDS orphans will be used further on in the dissertation).

The chapter starts with a general problem statement that serves as a rationale for conducting the research. Thereafter the research problem is formally stated in terms of a primary research question and related secondary research questions. Subsequently, the aim of the research is stated and a description is given about the research design and methodology that was followed in order to conduct the qualitative investigation.

The researcher identifies the ethical considerations that were adhered to in the qualitative part of the research and the chapter concludes with a list of chapters included in the dissertation.

1.2. GENERAL PROBLEM STATEMENT

The HIV/AIDS pandemic is of global concern as Merson (2006) indicates in the following quotation: "*On June 5, 1981, when the Centers for Disease Control reported five cases of Pneumocystis carinii pneumonia in young homosexual men in Los Angeles, few suspected it heralded a pandemic of AIDS. In 1983, a retrovirus (later named the human immunodeficiency virus, or HIV) was isolated from a patient with AIDS. In the 25 years since the first report, more than 65 million persons have been infected with HIV, and more than 25 million have died of AIDS. Worldwide, more than 40 percent of new infections among adults are in young people 15 to 24 years of age*." (Merson, 2006:2414).

The preceding quote introduces us to what has globally become a great monster. Throughout sub-Saharan Africa in particular HIV/AIDS turned into an epidemic at the beginning of the new millennium. After the HI-virus had been isolated from a patient with AIDS in 1983, by the end of 1987, 50 000 AIDS cases had already been reported in the US (Curran, Jaffe, Hardy, Morgan, Selik & Dondero, 1988:610). As documented, in the late 1980's, advice was given to people to prevent the spread of HIV/AIDS by practicing careful heterosexual behaviour (Hearst & Hulley, 1988:2428). That the unhindered and rampant spread of HIV/AIDS until this present day has continued, is not surprising, considering the loss of values and the promotion of promiscuous sexual behaviour in our postmodern age (Veith, 1994:17).

The estimates about the number of people living with HIV/AIDS globally and in Africa differ somewhat. According to Foster and Williamson (2000:S275), 49.7 million HIV infections were recorded globally in the year 2000. However this statistic seems doubtful as the United Nations Programme on HIV/AIDS (UNAIDS) (Oburu & Palmerus, 2003:505) reported 34.3 million HIV/AIDS infections worldwide in 2000. Unfortunately, after the first 20 years of HIV/AIDS, by the year 2000, infections were still on the rise and could not be reversed (De Cock & Weiss, 2000:A3). UNAIDS (2008b:7) reports that between 30.1 and 36.1 million infections were estimated globally in 2008. The tragic consequence is that the worldwide epidemic of HIV/AIDS has left in its trail a multitude of social ills, disrupting the lives of families and communities (Chama, 2008:410).

A study done in KwaZulu-Natal, South Africa, regarding community views about HIV/AIDS, shed light on how the local population perceived the phenomenon of HIV/AIDS (Taylor & Kvalsvig, 2008). It should be mentioned that KwaZulu-Natal is the province in South Africa showing the highest HIV/AIDS incidence, namely 28% of the population (Gray, Ferrer & Ortmann, 2009:147). Taylor and Kvalsvig (2008:64) found that community members involved in their study had difficulty speaking about HIV/AIDS. Some people did not even believe there was such a thing as HIV/AIDS. When denial becomes a way of dealing with the problem of HIV/AIDS, its spread will only be furthered.

Another factor concerning HIV/AIDS perception that appeared prominently was blaming another person or entity for the acquisition of the disease. Blaming somebody else for an illness is particularly problematic as it does not make a person responsible for his/her actions and following consequences, but rather supports the victim idea. The victim idea strengthens a sexually promiscuous lifestyle and causes resistance to a behavioural change. If a person interprets an infection with HIV/AIDS as caused by a force outside of him/her, the need for behaviour change is denied, and the power of choice driving that change is weakened. Interestingly, in Taylor and Kvalsvig's article (2008:65), even a traditional healer noted that "*very few clients acknowledged that the cause of their symptoms was HIV-infection: most considered that they had been bewitched*." It should be kept in mind though that the views presented in Taylor and Kvalsvig's study cannot be generalised to the South African population as a whole. It does remain a tragic reality, however, that most new infections unfortunately will continue to take place in third world contexts (De Cock & Weiss, 2000:A3).

Hunter (2002:100) also identifies prostitution as an *"important factor driving HIV infection",* but nevertheless argues that in the light of the high prevalence of HIV/AIDS in South Africa, most people clearly contract the disease in a different way. Nevertheless, the fact that drug abuse most frequently goes hand in hand with prostitution globally (Beckerleg, 2008:1170), indicates that prostitution could be regarded as a channel through which HIV/AIDS can be readily transmitted. Forty-three percent of fifteen- to nineteen-year-old girls in KwaZulu-Natal were found to be HIV positive during a voluntary testing study. This shocking reality raises great concern about sexual behaviour and lifestyles among the youth (Hunter, 2002:100). The question is also how the youth can be protected against sexual exploitation. A further implication of this finding is that thousands of children of HIV positive teenage mothers will become orphans who might need institutionalised care.

A factor not to be excluded in the spread of HIV/AIDS is migration. Hunter (2002:100) mentions that Sundumbili (a township of Mandeni 100 kilometres north of Durban, South Africa) was described by a magazine as *"Death City...The AIDS capital of KwaZulu-Natal",* and this happened after Mandeni started to attract hosts of migrants from the 1970's onwards from Northern KwaZulu-Natal. Hunter (2002:100) also refers to so-called 'transactional sex' as one of the main driving factors in the transmission of HIV/AIDS in Mandeni. Transactional sex is similar but not equivalent to prostitution. Transactional sex involves multi-partnered sexual relationships, but in contrast to prostitution, the people involved are called 'girlfriends' and 'boyfriends' in contrast to 'clients' and 'prostitutes' (Hunter, 2002:100-101). The UNAIDS report of December 2009 confirms as related previously, that mobile circumstances as displayed by migration augment the possibility of infection with HIV/AIDS. Furthermore, sex work, mother-to-child transmission, drug abuse by injection and medical injections are mentioned as possible modes of HIV/AIDS transmission (UNAIDS, 2009:32, 35-36).

During the last decade, South Africa has become the country with the highest HIV/AIDS incidence in Africa. This fact is substantiated by Bradshaw, Johnson, Schneider, Bourne and Dorrington (2002) when they state that "*Currently there are more people infected with HIV in South Africa than in any other African country - and ultimately we are likely to have to look after the highest number of AIDS orphans*". Various other sources confirm that sub-Saharan Africa with South Africa at its tip, is the geographical region that is most severely affected worldwide (Lalthapersad-Pillay, 2008; Ssengozi, 2007; Nyambedha, Wandibba & Aagaard-Hansen, 2003; Oburu & Palmerus, 2003). Judging from the large numbers of HIV/AIDS infections, the countries south of the Sahara will need to take care of an increasing number of orphans.

According to estimations by UNICEF, 20 million children will have been bereaved of one or both parents by 2010, and this mainly as a direct consequence of HIV/AIDS deaths (Freeman & Nkomo, 2006:302). It is expected that by 2015, about one out of three children in our country under the age of 18 will have been bereaved of one or both parents as a result of the disease (Freeman & Nkomo, 2006:302). This number is staggering, as it signifies that around 30% of South Africa's children will be orphaned due to HIV/AIDS within a few years' time.

A study conducted on the socio-demographic characteristics of HIV/AIDS in Nigeria, Lagos State, revealed that 66% of female respondents and 44% of male respondents in the age group 21-40 years were HIV-positive (Oluwagbemiga, 2007:671). This finding can be seen as representative of many an African country and illustrates that most deaths will occur among the child-bearing age group. The large number of deaths within the child-bearing age group proves to be very problematic in the light of the fact that "*keeping parents alive is the most effective preventive intervention*" in view of the orphan crisis (Freeman & Nkomo, 2006:302). However, this type of intervention is increasingly difficult since Antiretroviral Medicines (ARVs) are not widely available and too expensive for many Africans to afford. The sharply rising number of new HIV/AIDS infections in sub-Saharan Africa makes intervention through support programmes difficult (Levy, Miksad & Fein, 2005:498).

Traditionally, the extended family network is the preferred way in which orphans are being taken care of in the African context (Taylor & Kvalsvig, 2008:61). However, and not surprisingly, Lalthapersad-Pillay (2008:148) states that in countries where HIV infections are epidemic, the number of orphans have increased to such an extent that the extended family system struggles to provide for all these youngsters. Numerous other sources also confirm that the extended family system may not be able to cope as well as is often expected with the orphan problem in African countries (Lalthapersad-Pillay, 2008; Heymann, Earle, Rajamaran, Miller & Bogen, 2007; Stover, Bollinger, Walker & Monasch, 2007). Despite the fact that extended families can act as substitute families, AIDS orphans often have to face the trauma of being separated from their siblings after their parents' death (Landry, Luginaah, Maticka–Tyndale & Elkins, 2007). This problematic state of affairs is confirmed by Freeman and Nkomo (2006:302) Nyambedha *et al.* (2003:301) and Stover *et al.* (2007:21).

In South Africa, the high unemployment rate is also a significant contributor to the fact that the extended family system is under strain (Taylor & Kvalsvig, 2008:61). Third world countries' social systems are radically underdeveloped which means that financial support from the state is

insufficient. Caregivers struggle with a situation where they are burdened with the care of additional children without having the time to take on extra jobs in order to generate greater income (Heymann *et al.*, 2007:337). These factors constraining care given to AIDS orphans by the extended family illustrate that in spite of the often mentioned disadvantages of institutionalised care, present circumstances do show that there is definitely a demand for placement of AIDS orphans outside of the extended family system (Freeman & Nkomo, 2006:302). Intervention programmes in institutionalised care need to be carefully planned, based on extensive needs assessments of AIDS orphans, in order to best prepare them for a stable and productive adult life. This aspect is of vital importance for our country's socio-economic future.

In order to plan and implement programmes that aim at supporting AIDS orphans so that they can become stable and healthy citizens who can contribute meaningfully to the future of our country, we need to become fully aware of the whole spectrum of their developmental needs. In the light of the afore-mentioned, it is evident that an investigation into the psycho-educational needs of AIDS orphans should be undertaken in order to optimally support them towards a meaningful adulthood.

1.3. CLARIFICATION OF CONCEPTS

For the purposes of this study, "psycho-educational needs" refer to the psychological (emotional, intellectual, social and moral) as well as educational (to be fulfilled by parents in the family situation) needs of AIDS orphans.

AIDS orphans are defined as children under the age of 18 who have lost one or both parents to HIV/AIDS. Strictly speaking AIDS orphans can be divided into maternal, paternal or double orphans, but for the purposes of this study, any child who has lost at least one parent to HIV/AIDS will be considered a child orphaned by AIDS.

1.4. RESEARCH PROBLEM

In the light of what has been written in the general problem statement (paragraph 1.2.), the research problem is stated in terms of the following primary and secondary research questions:

1.4.1. Primary research question

- What are the psycho-educational needs of AIDS orphans as perceived by their caregivers at two day care centres situated in rural areas of KwaZulu-Natal?

1.4.2. Secondary research questions

- Which factors are impeding the psycho-educational development of these AIDS orphans?
- How do day care centres meet the psycho-educational needs of these AIDS orphans?
- What further support should be given to these AIDS orphans at the day care centres to enhance their psycho-educational development?

1.5. AIM OF THE RESEARCH

Related to the research questions the primary aim of the research is to:

- Identify and describe the psycho-educational needs of AIDS orphans as perceived by their caregivers at two day care centres situated in the rural areas of KwaZulu-Natal.

Related to the primary aim of the research, the secondary research objectives are to:

- identify and describe factors that impede the psycho-educational development of these AIDS orphans;
- determine how these day care centres meet the psycho-educational needs of AIDS orphans;
- make suggestions for further support that could be rendered to these AIDS orphans at the day care centres in order to enhance their psycho-educational development.

1.6. RESEARCH DESIGN AND METHODOLOGY

In this section, a very brief overview is given about the research design and methodology that was followed in the research, because these aspects are fully elaborated upon in Chapter 4.

1.6.1. Research design

The present study has made use of an interactive and qualitative research design. In other words, a phenomenological/interpretive design was chosen which attempts to incorporate the *"lived world or lived experience"* (Richards & Morse, 2007:49) of the participants in the study as much as possible. The empirical investigation took place at the sites where the participants in the research lived on a day-by-day basis, and in this way, justice was done to the qualitative premise of gaining real life experience of the setting in which the studied behaviour naturally occurs. The researcher herself travelled to the sites where the AIDS orphans lived on a day-to-day basis in order to get a personal idea of what life is like for these children in the circumstances which surround them.

Through in-depth interviews with the orphans' caregivers, data was gathered which provided insight into the particular needs of AIDS orphans and measures that could be taken to address their needs and that could assist and support them in their psycho-educational development. Due to considerable ethical dilemmas, the AIDS orphans themselves were not interviewed. Seeing that their caregivers spent a great deal of time with the orphans on a daily basis, they were more than able to share their views with regard to the varied needs of the orphans with the researcher. They were also knowledgeable concerning the extent to which these care centres could fulfil the needs of these orphans.

1.6.2. Research methodology

1.6.2.1. Site and participant selection

The present study included two day care centres in rural KwaZulu-Natal where AIDS orphans were cared for on a daily basis. The practicality of the sites lay in the fact that the caregivers of the AIDS orphans had immediate and daily experience of these children placed under their care. Furthermore, the caregivers were thought to give more objective information of the lives of AIDS orphans than family members who may have other interests besides full-time care for AIDS orphans. Their intensive involvement with the AIDS orphans placed caregivers in the best position to give elaborate information on developments in the AIDS orphans' lives.

1.6.2.2. Data collection strategy

The data collection strategy chosen, which should match phenomenological tenets, were in-depth interviews including narrations (Bloor & Wood, 2006:129) by the participants. Lived experiences stood in the foreground and participants were encouraged to elaborate on the needs of AIDS orphans which were placed under their care. Individual accounts including AIDS orphans' stories were encouraged since these were likely to capture the lived experiences of these children.

1.6.2.3. Data analysis

Transcription of the translations followed the interviews with the caregivers at the day care centres. The researcher used many hours to transcribe all the translated interviews word by word in order to correctly reflect what was said during the course of the interviews. The method of inductive content analysis was used. The raw data was taken, pieces of information singled out from the rich data available, and codes were then assigned to these pieces of information. The codes were screened in search of emerging categories. Axial coding was then used to combine

codes in order to form broader categories. These categories then became themes which represented the needs of AIDS orphans during the data-collection process of this study.

1.6.2.4. The trustworthiness of the research

To ensure trustworthiness of the research findings, the following measures were taken: The participants were regarded as partners in the knowledge-building process. Repeated interviews with participants kept the researcher from relying too much on inference (Maxwell, 2005:110). The findings emanating from the data were presented to the participants for reflection and subsequent feedback (so called member-checking). Thus, the researcher was given the opportunity to see whether she had interpreted the information the way participants had originally intended it and could make changes where necessary. Furthermore, the researcher employed the services of an independent co-analyst to determine whether the process of data analysis had been done correctly and whether the co-analyst's findings concurred with the findings of the researcher. The researcher also conducted a literature control to determine whether her research findings were supported by related research findings and theories about the psycho-educational development and needs of AIDS orphans.

1.7. ETHICAL ASPECTS

The researcher conducted the research at the day care centres with the written permission of the management of these institutions and all the participants (caregivers) participated on an informed and voluntary basis (see Appendix A for the letter of consent signed by the participants and Appendix C for the letter of consent from the manager of the organisation).

The researcher submitted an ethics application to the Ethics Committee of the North-West University (Potchefstroom Campus) to conduct the research. The necessary ethical clearance was granted to the researcher (see Appendix E) and the researcher undertook to conduct the research in compliance with the ethics research policy of the North-West University. This entailed adherence to ethical principles such as voluntary and informed participant consent, confidentiality, anonymity, as well as adhering to the principle that the research may not harm participants in any way (Richards & Morse, 2007:235).

1.8. CONTRIBUTION OF THE STUDY

1.8.1. Contribution to the subject area

The researcher hopes that the study will contribute towards a better understanding of the psycho-educational needs of AIDS orphans and how to optimally address these needs in care centres.

1.8.2. Contribution to the Research Focus Area

This study links with the research programme: "*Creation of sustainable support and working environments in diverse educational contexts*" of the Research Focus Area of the Faculty of Education Sciences.

1.9. PRELIMINARY CHAPTER DIVISION

This dissertation consists of the following chapters:

Chapter 1: Orientation

Chapter 2: The HIV/AIDS epidemic in South Africa

Chapter 3: The psycho-educational development of children, with specific reference to children orphaned by AIDS

Chapter 4: Research design and methodology

Chapter 5: Findings, conclusions and recommendations