

THE DIFFICULTIES EXPERIENCED BY CAREGIVERS OF AIDS ORPHANS

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**A dissertation submitted in fulfilment of the requirements for the
degree**

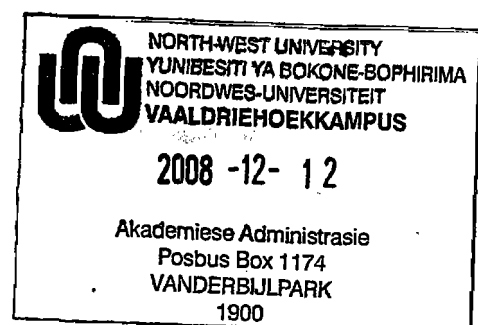
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DECLARATION

"I hereby declare that the thesis for the degree of Magister Educationis in Educational Psychology, at the North-West University hereby submitted, has not previously been submitted by me for a degree at this or any other university, that it is my own work in design and execution, and that all material contained herein has been duly acknowledged."

ELIZABETH QALIWE MOTAUNG

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ABSTRACT

The aim of this study was to identify difficulties experienced by caregivers of children orphaned by HIV/AIDS. This aim was achieved through the following objectives: investigate the family background of caregivers of AIDS orphans; investigate the general emotional impact of caring for AIDS orphans on caregivers; investigate the health impact of caring for AIDS orphans on caregivers; investigate the extent of financial impact of caring for AIDS orphans on caregivers; investigate the impact of caring for AIDS orphans on the social life of caregivers; to make recommendations so as to assist in helping caregivers.

A literature review and the qualitative empirical research method were used to achieve the aim and thus, the objectives stated above.

The literature review revealed the following difficulties experienced by caregivers of AIDS orphans: lack of knowledge regarding the formal adoption of orphans; lengthy process administered by an increasingly overstretched system; bad behaviour by orphans; stress resulting to poor physical and mental health, strained personal relationships and lowering of standards of care; poverty; "role strain" and "identity"; Interpersonal and family conflicts; isolation and fear for the future; excessive workload of having to care for children; and stigma and discrimination relating to HIV/AIDS.

However, this study highlighted the following difficulties: poverty; stress and depression; family fights; adoption; bad influence on orphans by neighbours; education; lack of training; lack of social services support; lack of community support structures; and lack of prior planning by orphans' parents.

The conclusions drawn from this study are that there were similar problems revealed in this study to those identified in the literature. For example, both literature and this study revealed poverty, stress and interpersonal and family conflicts as major problems experienced by caregivers. Grandparents and other family members who were caregivers in this study did not see "role strain" and "identity" as major stumbling blocks. Stigma and isolation were also some of the problems not directly experienced by most caregivers. However, it was evident that lack of involvement of some of these

caregivers with the community, has led to their not experiencing stigmatisation and isolation.

The following recommendations were made: caregivers should be given adequate training on how to use the grants given to orphans; researchers should use their research findings to influence government policy regarding termination of grants for orphans, that is, as long as orphans are still attending school or university, grants should not be terminated; universities and government should set aside special bursaries or study loans for orphans at universities, and these loans must only be paid when the orphans are in the position to do so; government should make extra funds available to give to caregivers as incentives; social Welfare Department should be strengthened so that free counselling could be given to caregivers whenever is necessary; School-Based Support Teams (SBST) committees in schools should be capacitated and empowered; capacitate and empower non-governmental organisations (NGOs); and there should be a strong interaction between schools, NGOs, social workers, nurses and police.

Limitations of the current study were also identified. This study could not show with absolute certainty whether the problems identified are related to orphanhood in general, rather than orphanhood by HIV/AIDS. Thus it was deemed necessary in future to have a comparison group of caregivers of orphans due to reasons other than HIV/AIDS.

Other limitations included reliance on one population race. The study cannot ascertain whether these findings can be applicable to caregivers from other race groups such as white or coloured races. South Africa is a multicultural society with different norms and values. Thus, the way we react to certain stimuli might be influenced to a large extent by our customs and values.

Further limitations included reliance on one specific type of caregiving. The study did not explore other type such as orphanages, but concentrated on what is regarded as the traditional safety net.

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CHAPTER ONE

ORIENTATION

1.1 INTRODUCTION

According to estimates from the Joint United Nations Programme On HIV/AIDS and According to estimates from the Joint United Nations Programme On HIV/AIDS and World Health Organisation (UNAIDS/WHO) AIDS Epidemic Update (2007:4), around thirty-point-eight million adults and two-point-five million children in the world were living with HIV at the end of 2007. Cluver **and** Gardner (2006:2) argue that an estimated twenty-four-point-eight per cent of South Africa's population are HIV positive, with four-point-seven million infected by 2001. They further assert that numbers of children parentally bereaved by AIDS in South Africa are expected to rise from one-point-one million in 2003, to three-point-one million by 2010. These numbers, as they suggest, would peak at five-point-seven million in 2015. The human toll and psychosocial and economic suffering of people due to HIV/AIDS is already enormous. For example, Avert (2005:3), in a study that was conducted in South Africa, found that already poor families coping with an AIDS-sick member were reducing spending on basic necessities like clothing by twenty-one per cent, electricity by sixteen per cent and other services such as water and transport by nine per cent. This impact on household income has in turn lead to some children going to school without food and/or proper school uniform, and further leading to these affected learners being discriminated against by educators, fellow learners or both.

According to Monasch **and** Boerma (2004:S55), the AIDS epidemic has caused rapid recent increases in the prevalence of orphanhood. They further argue that although high levels of adult mortality resulted in high levels of orphanhood in the era before AIDS, there is now a clear evidence of an increase in orphanhood in countries severely affected by HIV/AIDS. Throughout Africa, South Africa not exempted, large numbers of children are being orphaned by HIV/AIDS epidemic. Foster (2002:3) argues that this is generating serious psychological, social and economic problems for such children. Foster (2002:3) further suggests that many children who are not themselves infected, suffer the consequences of prolonged parental illness, and many others have already experienced the loss of their mother, father, or both. Due to this prolonged illness or loss of their parents, many of these children are forced to live with caregivers, which is

an indication that children orphaned by AIDS experience psycho-social and economic problems long before the death of their parents.

This problem has led to the development of family coping mechanisms including placing children with relatives, foster families or in residential institutions in the belief that their material needs will be met (ISS/UNICEF, 2004:2). South Africa's orphaned children, which is also typical of all African countries, have traditionally been cared for within the extended family, often by elderly grandparents (Foster, 1998:517). However, these mechanisms are showing signs of failure and this has led to the establishment of child-headed households (Olsen, 2005:1). The main event that leads to establishment of child-headed household is the death of parents, parental illness or disability. However, in some cases one or both are still alive (Alliance, 2006:1).

A study conducted by Nakiyingi, Bracher, Whitworth, Ruberantwari, Busingye, Mbulaiteye and Zaba (2003:1828) found that whereas infection may directly affect child mortality, unaffected children may also experience higher mortality if they are orphaned or if family resources are diverted to care for HIV-infected parents. The most unpleasant situation is having these learners taking on more responsibility to earn an income to produce food as well as taking care for family members. This situation forced the International Labour Organisation International Programme on the Elimination of Child Labour (ILO/IPEC) to commission in 2001 qualitative rapid assessments (QRAs) in four countries in sub-Saharan Africa, namely South Africa, the United Republic of Tanzania, Zambia and Zimbabwe (Amorim & Piprel 2003:2).

The most visible effects of the epidemic are a decline in school enrolment, which impacts on both learner as well as the education sector (Pharoah & Weiss, 2005:1). This highlights the fact that fewer children will receive basic education, which in South Africa is the basic right enshrined in the Bill of Rights (SA, 1996) The decline in school enrolment has a direct effect on HIV prevention because children who are supposed to be at schools end up not being effectively educated on the nature, extent and the impact of this disease on human development. Piot (2005:6), who is the Director of UNAIDS illustrates the relationship between education and AIDS when he posits that without education AIDS will continue its rampant spread in communities and affecting the lives of many people, including children. Consequently, with AIDS out of control, education will be out of reach of many children.

This importance of education to stop the spread of AIDS is further emphasised by Boo (2005:7), the Gauteng Education department's HIV and AIDS Education coordinator, who remarks that schools are critical vehicles to help reduce the spread of HIV and AIDS in Gauteng. Boler and Jellema (2005:11) best describe education as a social 'vaccine'. According to Boler and Jellema (2005:11), school systems have a three-fold role to play in fighting AIDS, namely:

- education protects individuals, and completion of at least primary education is directly correlated with dramatic reductions in HIV infections even if learners are never exposed to any specific AIDS education or life skills programme in the classroom. They argue that a general foundation in education equips individuals with cognitive skills needed to understand, evaluate and apply health information;
- education also boosts earning power, self-confidence and social status, giving young people and especially women increased control over their sexual choices;
- schooling is a sustained and powerful socialisation process (including in sexual education), shaping values, identities and beliefs through daily exposure to the nature of sexually transmitted diseases; and
- education informs individuals because schools have the potential to be inexpensive vehicles for passing on HIV/AIDS information and promoting safe behaviour among learners, since they reach the right target group (children and adolescents).

Wijngaarden, Mallik and Shaeffer (2004:3) argue that the education sector should be used as a vehicle to reduce the fear of HIV/AIDS and fear of people who have HIV/AIDS so that stigma and discrimination targeted towards this group is lessened by promoting care, compassion and non-judgemental attitudes among learners. Stigma and discrimination may lead to many forms of social exclusions, for example at home, and family, and school settings, including health-care facilities in communities and in societies in general (Gifford, 2003:3). Stigma and discrimination resulting from home and family settings may lead to the following (Gifford, 2003:4):

- shortened life span or increased illness in children affected by HIV because of neglect by caregivers;

- rejection of orphans by extended families, leading to child-headed households in the community. Caregivers may also feel that these orphaned children are difficult to stay with and therefore a social burden to them; and
- verbal abuse, for example regular reminders from relatives that they have been orphaned due to AIDS) and physical or sexual abuse

At the end of 2006, women accounted for fifty per cent of all adults living with HIV worldwide, and for sixty-one per cent in sub-Saharan Africa, which is an indication that the majority of AIDS orphans are motherless (UNAIDS/WHO AIDS Epidemic Update, 2006:1). Young people (under twenty-five years of age) account for half of all new HIV infections worldwide, which is an indication that AIDS orphans are still going to be a reality in South Africa because most of the persons in this age group could die untimely. In developing and transitional countries, seven-point-one million people are in immediate need of life-saving AIDS drugs; of these, only two-point-zero-one-five million (28%) are receiving the drugs (UNAIDS/WHO AIDS Epidemic Update, 2006:3).

1.2 SIGNIFICANCE OF STUDY

In September 2003, Lewis (2007:1), the UN Secretary-General's Special Envoy for HIV/AIDS in Africa spoke about the AIDS orphan problem, like this: "... in Zambia, [we] were taken to a village where the orphan population was described as out of control. As a vivid example of that, we entered a home and encountered the following: to the immediate left of the door sat the 84-year-old patriarch, entirely blind. Inside the hut sat his two wives, visibly frail, one 76, the other 78. Between them they had given birth to nine children; eight were now dead and the ninth, alas, was clearly dying. On the floor of the hut, jammed together with barely room to move or breathe, were 32 orphaned children ranging in age from two to sixteen... It is now commonplace that grandmothers are the caregivers for orphans". "The grandmothers are impoverished, their days are numbered, and the decimation of families is so complete that there's often no one left in the generation coming up behind. We're all struggling to find a viable response, and there are, of course, some superb projects and initiatives in all countries, but we can't seem to take them to scale". Additionally, the Executive Director of UNICEF, Carol Bellamy stated that: "The silence that surrounds children affected by HIV/AIDS and the inaction that results is morally reprehensible and unacceptable. If this situation is not addressed, and not addressed now with increased urgency, millions of children will

continue to die, and tens of millions more will be further marginalized, stigmatized, malnourished, uneducated, and psychologically damaged” (Bellamy, 2007:3).

It is evident that AIDS orphans will continue to be a reality in South Africa and furthermore caregivers would continue to provide care for these orphans. However, in order to find viable responses to this catastrophic problem, we need to investigate other problems encountered by these caregivers, apart from poverty. This might help to start new projects or initiatives, or even take already existing projects and initiatives to scale.

1.3 STATEMENT OF THE PROBLEM

South Africa has the most Aids orphans in the world, according to a United Nations Children’s Fund (2007:4) report released in January this year. According to this report, South Africa has approximately one-point-two million children who have lost one or both parents to AIDS, and it is estimated that by 2020 one in five children could be orphans if parental deaths continue at the same rate as seen over the past ten years. According to Alcorn (2007:1), AIDS orphans in South Africa suffer significantly higher levels of psychological distress than other orphans. A study conducted by Oxford University and Cape Town Child Welfare found high levels of psychological distress in AIDS orphans. The research team, led by Culver (2007:1), interviewed one-thousand-and-twenty-five (N=1 025) children aged ten to nineteen years in poor neighbourhoods of Cape Town using a standardised questionnaire. Children orphaned by AIDS were compared with children orphaned by other causes, and non-orphaned children. Culver (2007:1) collected information on socio-demographic factors and selected poverty indicators, household employment, food security, social security and school access. Culver (2007:1) found that children orphaned by AIDS had significantly poorer psychological health than other children in the study, and suffered levels of post-traumatic stress equivalent to those of children experiencing sexual abuse.

According to Culver’s (2007:1) report, AIDS orphans were less likely to have psychological ill health if they lived in a household with access to social security grants, food security and at least one member in employment, suggesting that efforts to alleviate poverty could mitigate the psychological problems manifesting as depression and delinquency in AIDS orphans. Culver (2007:1) posits that if AIDS orphans are given

enough food, enabled to go to school, and given a social grant, it reduces depression and behavioural problems. This report also highlights that, in South Africa, more than seven-point-one million children under fourteen-years-of-age are living in poverty — seventy-nine per cent of those eligible — were benefiting from the child-support social grant by April 2006. This represents a two-thirds increase since 2004 and a twenty-fold increase since 2000. More than three-hundred-and-twenty-five children were benefiting from foster care grants in 2006.

The above-mentioned report focused on data from 2005. It found that a total of fifteen-point-two-million children around the world had lost at least one parent to HIV/Aids. Most of these children were in sub-Saharan Africa, and one-point-two million were in South Africa. United Nations Children's Fund (2007:4) report also highlights that orphans:

- often lost out on schooling, food and clothing;
- may suffer anxiety, depression and abuse; and
- had a higher risk of exposure to HIV.

Orphans due to Aids are not the only children affected by the epidemic. Many more children live in households that have taken in orphans due to Aids. The United Nations Children's Fund (2007:4) report therefore estimated that about two-hundred-and-forty South African children under fifteen were HIV-positive, a figure matched globally only by Nigeria. About twenty-eight per cent of these children needed antiretroviral (ARV) treatment but only eighteen per cent of those who needed it were getting it. From the foregoing findings from the literature review, it is clear that AIDS orphans can place strain on households.

By 2010 more than one in five children in Botswana, Lesotho, Swaziland and Zimbabwe will be orphaned by AIDS (Children on the Brink, 2004:5). Alarming, the studies found that twenty per cent of households with children in Southern Africa are taking care of one or more AIDS orphans. About seventy-eight per cent of Zimbabwe's orphans and seventy-seven per cent of Botswana's had lost their parents to AIDS. Botswana, with twenty per cent of its children orphaned, has the highest rate of orphaning in sub-Saharan Africa, followed closely by Zimbabwe with nineteen per cent. More than fifteen per cent of children in Lesotho, Zambia, Swaziland, Mozambique and Angola were

orphans in 2003. About sixty-three per cent of Swaziland's orphans had lost their parents to AIDS, as was the case with sixty per cent of Zambia's orphans. According to Children on the Brink (2004:6), the number of AIDS orphans worldwide had shot up from 11,5-million in 2001 to 15-million in 2003.

From the latter statement it is clear that the worst may still be ahead of the world in as far as AIDS orphans is concerned - far too many parents will die as a result of AIDS. While not all orphaning is due to HIV/AIDS, orphaning remains the most visible, extensive, and measurable impact of AIDS on children. After losing parents and caregivers, children have an even greater need for stability, care and protection. HIV is a terrible disease because it starts to affect a child early in a parent's illness, and its impact continues through the course of the illness and throughout the child's development after the parent's death.

According to the Children on the Brink (2004:7), orphans are increasingly more likely to be living in households headed by females or grandparents. In Zambia, for example, female-headed households are twice as likely to care for double orphans, children aged less than eighteen years who have lost both parents, as male-headed households. Female-headed households also take in more orphans than male-headed households. In South African households that have assumed responsibility for orphans, there are on average two double orphans in each female-headed household, while in male-headed households the average is around one. The burden on grandparents and older caregivers is also increasing. In Namibia, for example, the proportion of double orphans and single orphans not living with a surviving parent being taken care of by grandparents rose from forty-four per cent in 1992 to sixty-one per cent in 2000. In the absence of their primary caregivers, AIDS orphans are more susceptible to:

- health risks;
- violence;
- Exploitation; and
- discrimination.

A study in rural Zimbabwe (Alcorn, 2007:1) showed that young people aged sixteen to twenty-one years had a significant burden of psychological well being problems, with

AIDS orphans most severely affected. Fifty-one per cent of one-thousand-four-hundred-and-ninety-five (N=1495) young people recruited as part of a larger study were found to have substantial mental ill health as measured by a locally validated psychological well being scale, and ten per cent said that they had thought about committing suicide in the previous week. Psychological well-being symptoms were associated with being stigmatised by others (72% vs 34%), having to work more than others (37% vs 17%), and being given less food (17% vs 6%) (all $p=0.0001$).

Maternal orphanhood was significantly associated with mental ill health. Cases had lower self-esteem as judged by responses to five questions and were more likely to be sexually active (66% vs 34%). Cases were also more likely to report forced sex or rape (7% vs 3%). Alcohol and drug use was higher among cases (60% vs 40%).

DeSilva (2007:1) and Culver (2007:1) assert that caregivers of AIDS orphans also report significantly poorer health than caregivers of other children. A study by the Boston University School of Public Health Centre for International Health and Development (Alcorn, 2007:1) found that the caregivers of AIDS orphans were significantly more likely to report ill health and to describe their health as poor, suggesting the high burden being placed on households that are caring for orphaned children. The research group found that the carers of orphans were older (50 years vs 45 years), less likely to be married or cohabiting, more likely to have cared for a sick adult child in the previous year, and likely to be caring for a larger number of children than the caregivers of non-orphans. The researchers concluded that caregivers of orphans, already under strain, are more vulnerable than others in society.

In the light of the foregoing literature review findings and DeSilva and Cluver's assertions, there is a need for the strategic framework for the protection, care and support of orphans and vulnerable children living in a world with HIV/AIDS as the best hope for pulling orphans and other vulnerable children back from the brink of despair, poverty, ill-health, uneducatedness. The strategy calls for:

- the strengthening of the capacity of caregivers by providing economic, psychological and other support;

- the mobilising and supporting of community-based responses to provide long-term assistance to vulnerable households;
- ensuring that orphans and vulnerable children have access to essential services, including education, health care and birth registration; and
- ensuring that governments protect the most vulnerable children through improved policies and legislation.

Having highlighted in the first paragraph of this section that South Africa has the most AIDS orphans in the world, this researcher has realized that there is a need to conduct research on the lived experiences of caregivers of AIDS orphans and ways in which the caregivers address the situation in which they find themselves. Little has been documented on the plight of extended family members such as grandparents, elder children who themselves are not yet matured adults, aunts, uncles and others that take care for AIDS orphans. Most researchers place more emphasis on the impact of HIV/AIDS on children and educators, and little emphasis has been placed on the impact of caring for AIDS orphans on the caregivers. For example, the emotional impact suffered by caregivers, as a result of having to listen to the abuses these orphans experience at schools or even in their neighbourhoods because of the death of their parents. The economic impact, due to shortage or insufficient government social grants may lead to poor caring, and under severe conditions, may even cause the death of those children who are themselves infected by the HIV virus. Therefore, the following questions arise:

- What is the family background of caregivers of AIDS orphans?
- What is the general emotional impact of caring for AIDS orphans on caregivers?
- What is the health impact of caring for AIDS orphans on caregivers?
- What is the extent of financial impact of caring for AIDS orphans on caregivers?
- What is the impact of caring for AIDS orphans on the social life of caregivers?
- Can a ecosystemic programme be proposed for helping caregivers of AIDS orphans give the best care to these children who may be vulnerable to discrimination, stigmatization, streetism (that is, children ending-up on the streets) and poverty?

1.4 AIMS OF THE STUDY

The aims of this study were to:

- investigate the family background of caregivers of AIDS orphans;
- investigate the general emotional impact of caring for AIDS orphans on caregivers;
- investigate the health impact of caring for AIDS orphans on caregivers?
- investigate the extent of financial impact of caring for AIDS orphans on caregivers;
- investigate the impact of caring for AIDS orphans on the social life of caregivers;
- propose an ecosystemic programme for helping caregivers of AIDS orphans give the best care to these children who may be vulnerable to discrimination, stigmatization, streetism and poverty.

1.5 THE RESEARCH METHODS USED TO CONDUCT THIS STUDY

A literature review and the qualitative empirical research method was used to answer questions raised in section 1.3 above, and to achieve aims of this study, which were mentioned in section 1.4 above. In the following paragraphs these research methods are briefly discussed.

1.5.1 Literature review

A literature review was done to acquire understanding of the theoretical framework of caregiving of AIDS orphans. To achieve this, all the available data bases (both national and international) were consulted during the study, for example, the NEXUS, SABINET – On-line, the EBSCOHost web and various other web-based sources as well as a DIALOG search were conducted to gather recent (from 1980-2007) studies on the subject. The following key concepts/words were used in the search: caregivers, caregiving, AIDS orphans, emotional problems, health problems, social problems, ecological and systems theories.

It ought to be mentioned that an on-line internet search was conducted in 2006 and 2007 on the above-mentioned key words.

1.5.2 Qualitative research

The research method used in this research is mainly qualitative. Coleman (1998:183), Verma and Mallick (1999:6) and Pogrebin (2003:4) define qualitative research as an inquiry process of understanding a social or human problem based on building a complex and holistic picture formed with words, reporting detailed views of informants and conducted in a natural setting. Denzin and Lincoln (1998:17) posit that one of the chief reasons for conducting qualitative research is that:

- not much has been written about the topic or population being studied;
- the research is exploratory; and
- the research seeks to pay attention to the ideas of informants and build a picture based on their ideas.

This method is deemed relevant to this research as it may afford the participants the opportunity to clearly state their opinions regarding their problems (Neuman, 1997:196). A qualitative research method was used to collect and analyze empirical research data and describe the meanings of the experiences the caregivers go through.

A purposive sample of twenty-nine participants (N=29) was interviewed. It is apparent that there are more caregivers than might be expected from a random sample. However, this sample is a purposive sample, selected to be maximally informative of a particular group, which is caregivers. The interviews were tape recorded in the local African languages such as IsiZulu, SeSotho, Setswana and IsiXhosa, transcribed *verbatim*, and translated into English.

1.5.3 A measuring instrument used for the qualitative research method

Self-developed interview schedules were used as empirical research data-gathering tools for administration during the interviewing process. An interview is a manner of finding out what is in or on someone else's mind, his or her individual lived experiences

and knowledge, opinions, beliefs, and demographic data (Reason & Bradbury, 2001:350). It is conducted face-to-face with the participants. Piantanida and Garman (1999:165) and Wragg *et al.* (2000:15) further assert that the interview may be primarily used as a strategy to collect narrative data and also for the researcher to develop insight into the way participants interpret the idea of their social context. The advantage of an interview is that it provides feedback immediately. Semi-structured interviews were conducted in this research to elicit information from the participants.

1.5.4 Demographic information

This research was conducted in the Gauteng Province's Vaal Triangle and the focus was on the population sample in Vanderbijlpark and Vereeniging districts. Sampling in Vanderbijlpark districts was done in Vabderbijlpark suburbs, Bophelong and Sebokeng townships. Sampling in Vereeniging districts focused in the Vereeniging suburbs. The exact total populations of caregivers in Vanderbijlpark and Vereeniging are not known. The sample population was drawn, mainly from cases supplied by the social workers and schools. The researcher personally knew only two cases.

The sample population for this research consists of:

- eleven caregivers of which two were grandparents (n=2), two children-headed families (n=2), one uncle (n=1), two aunts (n=2), three guardians (n=3), one-sister-in-law (n=1);
- two family member (n=2)
- nine non-governmental organization's advocates (n=9); and
- seven educators (n=7).

The eleven caregivers are representative of different groups of caregivers. The two family members, nine non-governmental organization's advocates and seven teachers were necessitated by the need to verify some of the information given by some caregivers.

1.6 CHAPTER DIVISION

The chapter division of this research is as follows:

- Chapter one provides an introduction, statement of the problem, significance of study, aims of study, and research methods of this dissertation.
- Chapter two consists of a literature review on the nature of the psychological, social and economic impact of HIV/AIDS on caregivers of learners orphaned due to HIV/AIDS
- Chapter three describes the empirical research design.
- Chapter four deals with the analyses and the interpretations of the empirical research data collected during interviews.
- Chapter five provides findings from the empirical research, recommendations and suggestions relevant to the ecosystemic programme for empowering caregivers of learners orphaned as a result of AIDS to provide the best care for these learners.

1.7 CONCLUSION

This chapter provided an orientation to the research. The next chapter provides literature review on HIV/AIDS, orphanage and caregivers.

CHAPTER TWO

LITERATURE REVIEW ON HIV/AIDS, AIDS ORPHANS AND CAREGIVERS

2.1 INTRODUCTION

Zaba, Whiteside and Boerma (2004:S1-S7) investigated about the demographic and socio-economic impact of the HIV epidemic in sub-Saharan Africa. They looked at the impact of the HIV epidemic on human mortality, policy-making and numbers of orphans that are growing in sub-Saharan Africa. It was also found that usually HIV/AIDS affects prime-age adults, with the consequences that the probability of a fifteen-year old dying before reaching the age of sixty-years has risen dramatically, from a range of ten per cent to thirty per cent in the mid-1980s, to a range of thirty per cent to sixty per cent at the turn of the twentieth century. It is thus indicated that many school-going children would have lost a father, mother or even both parents before they themselves reach adulthood.

With the spread of what is referred to in South Africa as informal settlements, there are many young men and women living in these communities under very difficult and trying social conditions. Many of these young people, of which the majority is young women, are not working and their means of survival is getting involved in sexual relationships with married men, as is evident from TV documentaries. It is shown that it is through these sexual relationships that many of these young parents contract HIV/AIDS and end-up dying through AIDS related illnesses such as opportunistic diseases such as, *inter alia*, weight loss; dry cough; recurring fever or profuse night sweats; profound and unexplained fatigue; swollen lymph glands in the armpits groin, or neck; diarrhoea that lasts for more than a week; white spots or unusual blemishes on the tongue, in the mouth, or in the throat; red, brown, pink, or purplish blotches on or under the skin or inside the mouth, nose, or eyelids; memory loss, depression, and other neurological disorders; tuberculosis, pneumonia, gastro-enteritis, meningitis; and cancer which seriously affect the psychological and the physical well-being of human beings (Kwatubana, 2005:1). This state of affairs results in their children being orphaned after their passing away.

The literature review (Foster, 2002:3) reveals that many AIDS orphans end up on the streets because their parents have died. They have either decided to live in the streets because they did not want to live with their caregivers. It is also predicted that by 2010, there will be around 15.7 million AIDS orphans in Sub-Saharan Africa (Avert, 2007:1). Children affected by HIV/AIDS are also forced to bear the trauma and hardship. For example, not only does HIV/AIDS mean children lose their parents or guardians, but sometimes it means that they lose even their childhood as well. Many of these affected children in sub-Saharan Africa have entered the world of work to supplement family income lost when an adult becomes ill or dies due to the HIV/AIDS epidemic (Avert, 2007:4). Some of these children without a strong community or family support structures end up in the streets in search of work to support themselves or their siblings who are either left in the care of relatives or are left alone at home. Child labour presents these children with numerous risks for both sexual exploitation and HIV/AIDS infections.

The International Labour Organisation International Programme on the Elimination of Child Labour (ILO/IPEC) commissioned qualitative rapid assessments (QRAs) in four countries in sub-Saharan Africa, namely, South Africa, the United Republic of Tanzania, Zambia and Zimbabwe in the year 2001 (Amorim & Piprel, 2003:2). The objective of this study was to better understand the complex relationships arising from the impact of the HIV/AIDS pandemic on child labour and the risks of HIV/AIDS infections to working children. The findings were expected to assist ILO/IPEC with further operational planning regarding policy and programme initiatives to eliminate child labour. The following three basic questions of the QRAs teams about the relationships between HIV/AIDS and child labour were asked:

- Are children entering the labour market, including the informal sector, as the result of the impact of HIV/AIDS on their families?
- Are working children at risk of sexual exploitation and HIV infection?
- Is the HIV/AIDS pandemic imposing a “care burden”, such as marked increase in domestic work and household chores on children?

Without strong family support, which is be provided by caregivers, many vulnerable children orphaned due to HIV/AIDS may escape the family safety net and be exposed to abuse in the form of child labour.

The ILO/IPEC (Amorim & Piprel, 2003:2) report provided the following evidence of the linkage between HIV/AIDS and child labour, which were:

- firstly, the linkage has been established for children who, through their involvement in the labour force, are at risk of becoming HIV infected and to suffer from AIDS and related illnesses. The ILO/IPEC gave the following reasons for the children's susceptibility to HIV/AIDS:
 - once in the workforce, the children may find life so precarious that survival sex, i.e. exchanging sex for food, clothing, or small amounts of money, becomes an option;
 - girls, and boys, may be drawn into sex work;
 - children may be exploited because of their vulnerability due to age, location or gender; and
 - if HIV infected, children are less likely to have access to proper nutrition, health care and drug treatments for opportunistic infection and AIDS.
- secondly, children who are from households affected by HIV/AIDS often must enter the labour force because families cannot meet their basic needs without contributions from the children. As a result, children may be subjected to harsh and exploitative conditions and sexual abuse. The effects occur under the following conditions:
 - children are withdrawn from school to reduce family expenses, and then seek work;
 - children are placed with extended family members, but are expected/forced to work; and
 - children flee new family arrangements because of depression, neglect or exploitation, and have to work.

The ILO/IPEC (Amorim & Piprel, 2003:2) study also found that the HIV/AIDS pandemic compounds the challenge of reducing child labour by increasing the:

- number of children in the labour force and vulnerable to exploitation;
- pressure on both households and the children themselves to have the children earn income instead of attending school [Thus rendering SASSA Act (84/1996) ineffective in the case of South Africa.];

- demands on public and private services, notably the delivery of effective health care for children and adolescents and, in the case of South Africa, grants for children and caregivers;
- burdens on community groups and institutions assisting caregivers and vulnerable children; and
- the risk that vulnerable children will engage in survival sex, thereby increasing their risk of HIV infection.

The following major reasons, which relate to HIV/AIDS pandemic, were given:

- the death of a parent, or the disappearance of the main income earner;
- the increased burden on the extended family of caring for children of households affected by HIV/AIDS;
- worsening economic conditions, nationally or locally;
- new poverty;
- the need to meet basic needs, especially that of food;
- providing support for themselves or siblings; and
- paying school fees.

Gerntholtz **and** Richter (2004:910) reported in 2002 that 13% of children aged between two and fourteen years in South Africa had lost a mother, a father or both. Gerntholtz **and** Richter (2004:910) reasoned that although there was no research examining the impact of HIV on the number of children who have been abandoned, anecdotal evidence suggests that children's homes are seeing steep increases in the number of children requiring care, and also many of those were infected. In fact, it was reported in 2004 that South Africa's child welfare system is under huge pressure to provide for the number of children orphaned by HIV/AIDS and seeking foster care (van Eyssen, 2004:4). It was also quoted in the same newspaper that the Actuarial Society of South Africa projects that by the end of 2005 close to one million children will be orphaned by the epidemic. It was estimated in 2004 that 18 percent of the country's children are Aids orphans and the Medical Research Council predicted that at least 5.7 million children could lose one or both parents by 2015.

Gerntholtz **and** Richter (2004:910) also cited the emergence of an increase in informal caregivers, who are classified as grandparents, aunts, uncles, siblings or sympathetic members of the community. These informal caregivers are not aware of the need to formalise the care relationship and those who do attempt to foster or adopt children in their care face a lengthy process administered by an increasingly overstretched social services system. These caregivers are therefore not recognised by law to give consent needed for the medical treatment of these children. The worst scenario is in the case where for example, the children would need antiretroviral therapy (ART) and this would rise to the unfortunate state of the affairs in which health worker, in keeping with the provisions of the Act and common law, would have to apply to the Minister of Social Development or the High Court for special permission to administer this treatment. Gerntholtz **and** Richter (2004:910) point the fact that with an increasing number of children being orphaned and abandoned by parents with HIV/AIDS, and in time requiring ART if they have contracted the virus, it is clear that the current legal arrangement creates an intolerable situation.

The emergence of community/home-based care programmes, which are often organised by people living with HIV/AIDS, has become one of the outstanding features of the epidemic (AVERT, 2005:2). These community-based care programmes offer an affordable option for the care of people affected and infected with the HIV/AIDS epidemic. These kinds of programmes have been used, especially in South Africa, to get information on the number of children who have become orphans, as well as tracing the orphanage homes, foster homes or relatives where these children are placed. It is estimated that at the end of 2001, eleven million children in sub-Saharan Africa should have been orphaned due to the loss of one or both parents because of HIV/AIDS (Amorim **&** Piprel, 2003:1).

This state of affairs has led to a global meeting to discuss the Demographic and Socio-economic Impact of the HIV/AIDS pandemic (ZABA, WHITESIDE **&** BOERMA, 2004:S1), which was held in Durban, South Africa, on 26-28 March 2003. The evidence of the impact of the HIV/AIDS pandemic presented in this meeting revolved mostly around sub-Saharan Africa and highlighted that with an estimated 26.6 million, HIV infections out of the global total estimate of 40 million by end-2003, and with an adult HIV prevalence at least ten times higher than in most other parts of the world, it was

clear that the magnitude of the impact of HIV/AIDS in sub-Saharan Africa on the population and economies is bound to be of an astronomical scale.

2.2 THE LATEST HIV/AIDS GLOBAL STATISTICS AND THE HAVOC IT CAUSES IN THE WORLD

The following latest statistics on the global effects of the epidemic of HIV/AIDS were published by UNAIDS/WHO in November 2007, and refer to the end of 2007.

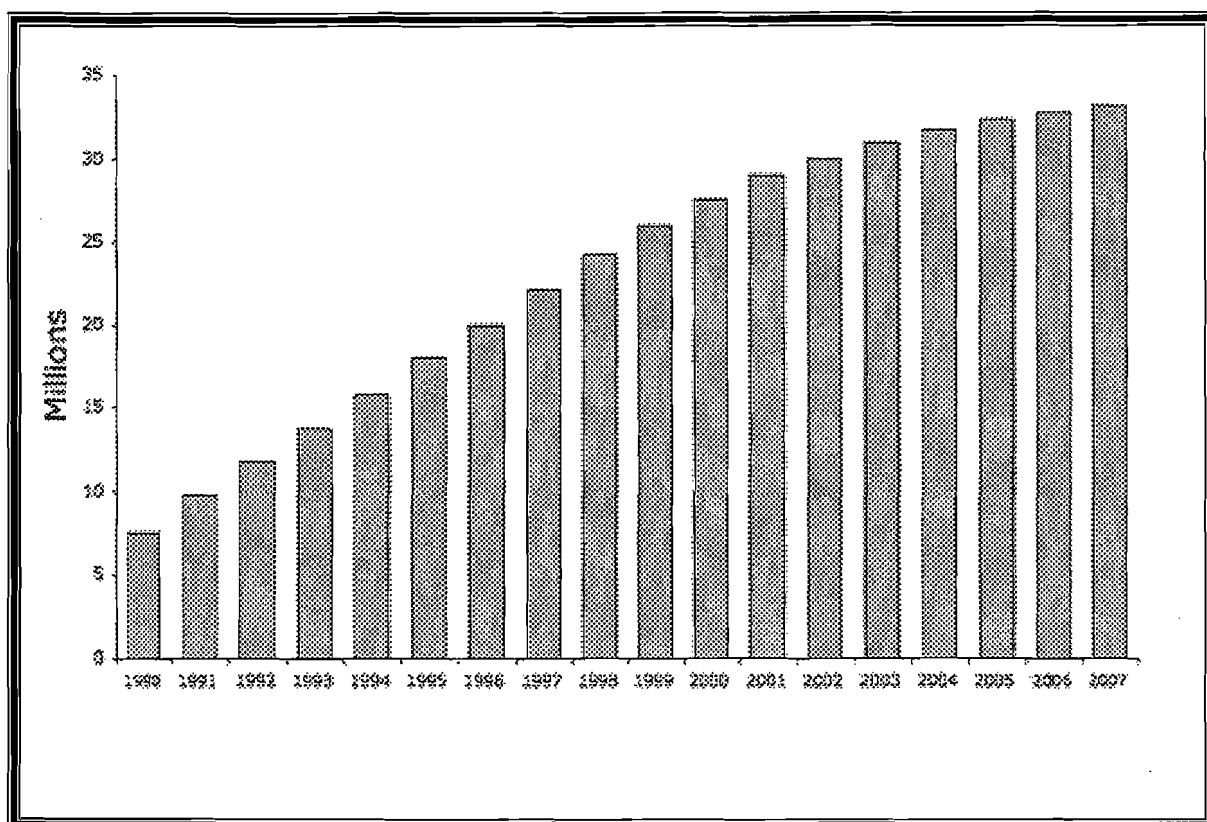
Table 2.1: 2007 world AIDS statistics

Variables	Estimate	Range
People living with HIV/AIDS in 2007	33.2 million	30.6-36.1 million
Adults living with HIV/AIDS in 2007	30.8 million	28.2-33.6 million
Women living with HIV/AIDS in 2007	15.4 million	13.9-16.6 million
Children living with HIV/AIDS in 2007	2.5 million	2.2-2.6 million
People newly infected with HIV in 2007	2.5 million	1.8-4.1 million
Adults newly infected with HIV in 2007	2.1 million	1.4-3.6 million
Children newly infected with HIV in 2007	0.42 million	0.35-0.54 million
AIDS deaths in 2007	2.1 million	1.9-2.4 million
Adult AIDS deaths in 2007	1.7 million	1.6-2.1 million
Child AIDS deaths in 2007	0.33 million	0.31-0.38 million

Source: (UNAIDS/WHO, 2007)

These figures suggest that there are more children being orphaned due to high adult deaths in 2007. In the light of Table 2.1 above, the global picture of the effects of the epidemic of HIV/AIDS on humankind could also be graphically represented in order to get a clearer picture of the escalation of the epidemic, which is:

Figure 2.1: Location of AIDS graphically represented



Source: (UNAIDS/WHO, 2007)

Figure 2.1 above shows that the number of people living with HIV has risen from around eight million in 1990 to more than thirty-three million in 2007, and is still growing.

The world's regional statistics for HIV/AIDS at the end of 2007 for adults aged between fifteen and forty-nine years, who were living with HIV/AIDS, was as follows:

Table 2.2: 2007 Regional statistics for HIV/AIDS

Region	Adults and children living with HIV/AIDS	Adults and children with newly infected	Adult prevalence	Deaths of adults and children
Sub-Saharan Africa	22.5 million	1.7 million	5.0%	1.6 million
North Africa and Middle East	380,000	35,000	0.3%	25,000
South and South-East Asia	4 million	340,000	0.3%	270,000
East Asia	800,000	92,000	0.1%	32,000
Oceania	75,000	14,000	0.4%	1,200
Latin America	1,6 million	100,000	0.5%	58,000
Caribbean	230,000	17,000	1.0%	11,000
Eastern Europe and Central Asia	1.6 million	150,000	0.9%	55,000
Western and Central Europe	760,000	31,000	0.3%	12,000
North America	1.3 million	46,000	0.6%	21,000
Global Total	33.2 million	2.5 million	0.8%	2.1 million

Source: (UNAIDS/WHO, 2007)

Table 2.2 depicts that around sixty-nine percent of people living with HIV are in sub-Saharan Africa. Table 2.2 also depicts that, during 2007, around two and a half million adults and children became infected with HIV, the virus that causes AIDS, and that, by the end of 2007, an estimated thirty-three-point-two million people worldwide were living with HIV/AIDS. The year (2007) also saw two-point-one million deaths from AIDS, despite recent improvements in access to anti-retroviral treatment.

From Tables 2.1 and 2.2 it can be deduced that AIDS is responsible for leaving vast numbers of children across Africa without one or both parents. Table 1 above shows the countries with the largest numbers of AIDS orphans.

In some countries, a larger proportion of orphans have lost their parents to AIDS than to any other cause of death - meaning that, were it not for the AIDS epidemic, these children would not have been orphaned. The second table shows the countries in which the children who lost their parents to AIDS make up the highest proportion of the total national number of orphans.

Most of the AIDS orphans who live outside of Africa live in Asia, where the total number of orphans - orphaned for all reasons - exceeds seventy-three million.

As the number of orphans varies between countries, so it varies between different regions within those countries. Particular areas may have higher or lower percentages of orphans, largely depending on the local HIV prevalence rates. There can also be

substantial differences between rural and urban areas.

The age of orphans, however, is fairly consistent across countries. Surveys suggest that overall about fifteen percent of orphans are zero to four years of age, thirty-five percent are five to nine years of age, and fifty percent are ten to fourteen years of age.

The scale of the orphan crisis is somewhat masked by the time lag between when parents become infected and when they die. If, as expected, the number of adults dying from AIDS rises over the next decade, an increasing number of orphans will grow up without parental care and love.

The increased spiral of adult deaths in so many countries means that the number of children orphaned each day is expanding exponentially. Africa is staggering under the load.

2.3 THE IMPACT OF HIV/AIDS ON CHILDREN

The biggest losers in the HIV/AIDS epidemic that has gripped the world are children. For example, according to the United Nations Children's Fund (2007:4) report, there is a total of fifteen-point-two-million children around the world who have lost at least one parent to the HIV/AIDS epidemic. Most of these children are in sub-Saharan Africa — and one-point-two-million were in South Africa. These are not the only South African orphans. This United Nations Children's Fund (2007:6) report estimated that two-point-five-million South African children under the age of eighteen years had lost at least one parent due to any cause, with about four-hundred-and-fifty-thousand having lost both parents.

For those countries with data, according to this United Nations Children's Fund (2007:6) report, only seven had children who had lost both parents, that is China, Democratic Republic of Congo, Ethiopia, India, Nigeria, Uganda and Zimbabwe.

The United Nations Children's Fund (2007:6) report highlights that orphans often loose out on schooling, food and clothing, they may suffer anxiety, depression and abuse, and they have a higher risk of exposure to HIV.

Orphans due to AIDS are not the only children affected by the epidemic. Many more children live with parents who are chronically ill, live in households that have taken in

orphans due to AIDS or have lost teachers and other adult members of the community to AIDS (United Nations Children's Fund, 2007:8).

This United Nations Children's Fund (2007:9) report estimated that:

- about two-hundred-and-forty thousand South African children under fifteen-years of age were HIV-positive, a figure matched globally only by Nigeria. About twenty-eight per cent of these needed anti-retroviral treatment but only eighteen per cent of those who needed it, were getting it;
- about one third of an estimated two-hundred-fifty-thousand HIV-infected pregnant mothers received anti-retroviral treatment. About a third received anti-retroviral treatment for prevention of mother-to-child transmission, which UNICEF said showed progress as this had increased from twenty-two per cent the year before; and
- only about sixty-four thousand of the babies born to HIV-infected mothers — about a quarter of them — started the medication cotrimoxazole prophylaxis, to prevent opportunistic infections that can be fatal.

The United Nations Children's Fund (2007:9) report said the virus progressed rapidly in children, with about a third dying before their first birthday and half of these children dead before their second birthday. In 2006 alone about three-hundred-and-eighty-thousand children died around the world from AIDS-related causes. The vast majority of these deaths were preventable, either through treating opportunistic infections with antibiotics or through antiretroviral treatment. The World Health Organisation recommends giving the medication cotrimoxazole to HIV-positive children and to babies born to HIV-positive mothers. Some of these children may have been under the care of caregivers, and thus may lead to these caregivers experiencing trauma.

It is interesting to note that this United Nations Children's Fund's (2007:6) report highlights that South Africa was one of a few countries which had been able to intensify HIV treatment of children by integrating this into HIV sites for adults.

Antiretroviral treatment for children now cost about sixty-dollars a year (about four-hundred-and-twenty-rands) (United Nations Children's Fund, 2007:4). The United Nations Children's Fund (2007:4) estimates that five per cent of South African boys

aged between fifteen and twenty-four years and fifteen percent of the girls that age were HIV-positive. According to this report, about eighteen per cent of South Africa's adults were estimated to be HIV-positive.

The United Nations Children's Fund (2007:4) said child grants helped to alleviate poverty. For example, in South Africa, for example, the country with the largest number of orphans due to Aids, more than seven-point-one-million children under fourteen living in poverty — seventy-nine per cent of those eligible — were benefiting from the child-support grant by April 2006. This represents a two-thirds increase since 2004 and a twenty-fold increase since 2000. More than 325 000 children were benefiting from foster care grants in 2006.

By 2014, according to the United Nations Children's Fund's (2007:9) report, the above mentioned figure of AIDS orphans in South Africa, which is projected on current infection and death rates, could be eleven-point-five million. It is not surprising to note that, both in the whole world and world's regions, the figures on HIV infections and AIDS deaths have seen more than fifteen million children under the age of eighteen years being orphaned. More than twelve million of these children live in Sub-Saharan Africa, where it is currently estimated that nine per cent of all children have lost at least one parent to AIDS. As HIV infections become increasingly common among the adult population of the region, the brunt of HIV-associated mortality is expected to occur within this decade; and as a result, millions of children will lose parents to AIDS. By 2010, it is predicted that there will be around fifteen-point-seven million AIDS orphans in Sub-Saharan Africa.

If the above situation is not addressed, and not addressed at this stage with increased urgency, tens of millions of children will be orphaned, marginalized, stigmatized, malnourished, uneducated, and psychologically damaged (United Nations Children's Fund's, 2007:9). There is an urgent need to help, care and protect these children. In many countries, a variety of initiatives are now taking place to help AIDS orphans. The number of children requiring support is increasing rapidly, though, and in many instances the increase in response is not keeping up with the increase in need. Social support responses need to be scaled up, and this is going to need increases in both financial resources and commitment over the next few years.

The other three of the African countries that have been worst affected by HIV and AIDS are Botswana, Malawi, and Zambia (United Nations Children's Fund's, 2007:9). In Botswana, it is estimated that 120,000 children had lost their parent(s) to AIDS by the end of 2005. As a result of this, the Botswana government established a National Orphan Programme in April 1999 to respond to the immediate needs of orphaned children, and a comprehensive policy for helping AIDS orphans was established under this Programme. The government currently runs a 'food basket' scheme, where a basket of food is provided to orphaned households once a month. Orphans are also provided with school uniforms and are subsidised for transportation fees to get to school, among other things. By December 2005, fifty-thousand-and-five-hundred-and-fifty-seven orphans were registered to receive support from the government.

An example of the programme in action is the rural district of Bobirwa, where district authorities have contracted the Bobirwa Orphan Trust to deliver essential services to orphans in the area (United Nations Children's Fund's, 2007:7). The Trust is made up of community volunteers and government paid employees, including social workers and family welfare educators. Members of the Trust register orphans in the district and identify their needs through home visits, schools and churches. They also initiate community-based foster placements, and support the provision of food and clothing to orphans through local groups. On top of this, needy orphans are assisted with blankets, counselling, toys, bus fares to and from school, school uniforms and other educational needs.

Traditionally, orphaned children in Botswana have been cared for by extended families. However, due to social and economic strain some families are no longer willing - or indeed able - to do this. Even when they are, the level of care orphans receive is sometimes unacceptable. In some cases, families have been known to take on orphans merely to benefit from government orphan packages (United Nations Children's Fund's, 2007:7).

A variety of different community organisations do now provide support for orphans, and the government does encourage communities to provide care for orphans within the community, and to rely on institutional care only as a last resort (United Nations Children's Fund's, 2007:7).

The Kgaitisadi Society in Gaborone is an example of a community organisation set up to care for and educate AIDS orphans (United Nations Children's Fund's, 2007:8). Established in 2002, it assists with their basic needs and provides basic and primary school level education through a flexible school programme. It also provides support for children caring for family members and for those that are working. Other examples of community organisations are the Maun Counselling Centre, and the House of Hope in Palapye both of which provide day care support for orphans.

AIDS, extreme poverty and food shortages have all taken their toll on Malawi in recent years. By the end of 2005, it was estimated that Malawi had over half a million children orphaned by AIDS (United Nations Children's Fund's, 2007:8).

As early as 1991, the Government of Malawi established a National Orphan Care Task Force (United Nations Children's Fund's, 2007:8). The Task Force is made up of various representatives and organisations, which are responsible for planning, monitoring and revising all programmes on orphan care. One year later, in 1992, National Orphan Care Guidelines were established. The guidelines serve as a broad blueprint to encourage and co-ordinate regional and community efforts. The Task Force has also established a sub-committee that is reviewing existing laws and legal procedures to provide greater protection to vulnerable children.

An important aspect of the government's strategy has been to promote and support community based programmes. In both rural and urban areas across Malawi, communities are developing a variety of ways to cope with the growing crisis of AIDS orphans. In many villages orphan committees have been established to monitor the local situation and to take collective action to assist those in need (United Nations Children's Fund's, 2007:8).

The Government furthered its commitment to AIDS orphans in June 2005 when their President launched The National Plan of Action for Orphans and Vulnerable Children. This plan, which is due to run until 2009, aims to increase access to essential services - such as education, health, nutrition, water and sanitation - amongst AIDS orphans and other vulnerable children. It also aims to help families and communities provide support for such children (United Nations Children's Fund's, 2007:8).

The large number of children losing parents to AIDS in Malawi presents a daunting challenge to both the government and regional communities (United Nations Children's Fund's, 2007:8). A severe lack of human and financial resources continues to hold back Malawi's fight against AIDS, including efforts to support AIDS orphans. Orphans have little food, few clothes, no bedding and no soap and as a whole, community care because of HIV/AIDS is overwhelmed and breaking down.

In Zambia the estimated number of children orphaned because of AIDS is seven-hundred-and-ten thousand (United Nations Children's Fund's, 2007:8). The AIDS epidemic in Zambia is among the worst in the world. Under the twin pressures of poverty and disease, many extended families (which traditionally care for vulnerable children in Zambia) are breaking down.

It is very hard to find a family in Zambia (United Nations Children's Fund's, 2007:8) that has not been personally touched. It is very hard to find a child that has not seen or witnessed a death related to HIV/AIDS. The extended family in the community structure, have really broken under the weight of the HIV/AIDS epidemic and poverty, and when the burden becomes too great, families are unable to cope any more, and as a result, tremendous numbers of orphans and children who are no longer able to be cared for by their extended family are noticed. In the midst of all that, it is seen that within the communities themselves and within extended families there are truly heroic efforts to absorb the children, to work with them, to give them the nurturing and caring in the environment, as well as in their own communities because it is so necessary for this next generation.

Child-headed households, once a rarity in Zambia (United Nations Children's Fund's, 2007:8), are now increasingly common. Unfortunately, formal and traditional inheritance, land ownership and health policies have not kept up with their needs. In July 2006, Zambia's Health Minister, Ronnie Shikapwasha, revealed that six percent of the country's AIDS orphans are homeless and that less than one percent lives in orphanages (United Nations Children's Fund's, 2007:8). He stressed that more needs to be done to support AIDS orphans, through better access to education, health care, nutrition, and food, among other things.

One multi-sectoral project in Zambia (United Nations Children's Fund's, 2007:9) is Strengthening Community Partnerships for the Empowerment of Orphans and Vulnerable Children (Scope-OVC). This support programme is implemented by CARE/Zambia with help from Family Health International (FHI) and funding from the United States Agency for International Development (USAID). Between 2003 and 2004, this project offered life-sustaining care and support services for over 81,709 children. The aim of the project is to keep siblings together and children within extended families and communities. Scope-OVC develops district and community level capacity and resources to respond to the needs of orphans and vulnerable children. Scope also tries to build partnerships and networks and sustain existing ones within community-based organizations that provide care and support for children.

These intervention strategies may go a long way in helping ease the financial burden on caregivers.

The emotional problems faced by AIDS orphans are discussed below (United Nations Children's Fund, 2007:9).

2.3.1 Emotional impact

Children whose parents are living with HIV often experience many negative changes in their lives and can start to suffer neglect, including emotional neglect, long before they are orphaned. Eventually, they suffer the death of their parent(s) and the emotional trauma that results. They may then have to adjust to a new situation, with little or no support, and may suffer exploitation and abuse.

In one study carried out in rural Uganda, high levels of psychological distress were found in children who had been orphaned by AIDS. Anxiety, depression and anger were more found to be more common among AIDS orphans than other children. Twelve percent of AIDS orphans affirmed that they wished they were dead, compared to three percent of other children interviewed.

These psychological problems can become more severe if a child is forced to separate from their siblings upon becoming orphaned. In some regions this occurs regularly: a survey in Zambia showed that 56% of orphaned children no longer lived with all of their

siblings.

2.3.2 Household impact

The loss of a parent to AIDS can have serious consequences for a child's access to basic necessities such as shelter, food, clothing, health and education. Orphans are more likely than non-orphans to live in large, female-headed households where more people are dependent on fewer income earners. This lack of income puts extra pressure on AIDS orphans to contribute financially to the household, in some cases driving them to the streets to work, beg or seek food.

The majority of children who have lost a parent continue to live in the care of a surviving parent or family member, but often have to take on the responsibility of doing the housework, looking after siblings and caring for ill or dying parent(s). Children who have lost one parent to AIDS are often at risk of losing the other parent as well, since HIV may have been transmitted between the couple through sex.

2.3.3 Education

Children orphaned by AIDS may miss out on school enrolment, have their schooling interrupted or perform poorly in school as a result of their situation. Expenses such as school fees and school uniforms present major barriers, since many orphans' caregivers cannot afford these costs. Extended families sometimes see school fees as a major factor in deciding not to take on additional children orphaned by AIDS.

AIDS orphans may also leave school to attend to ill family members, work or to look after young siblings. Even before the death of a parent, children may miss out on educational opportunities.

Outside of school, AIDS orphans may also miss out on valuable life-skills and practical knowledge that would have been passed on to them by their parents. Without this knowledge and a basic school education, children may be more likely to face social, economic and health problems as they grow up.

Boler and Jellema (2005:11-12) best described education as a social vaccine, and have suggested that school systems have a threefold role to play in fighting AIDS. Firstly, a

general foundation in education equips individuals with cognitive skills needed to understand, evaluate and apply health information. Secondly, education also boosts earning power, self-confidence and social status, giving young people and especially women, increased control over sexual choices. Again, schooling is a sustained and powerful socialisation process, which shapes values, identities and beliefs through daily exposure. Lastly, education informs individuals because schools have the potential to be inexpensive vehicle for passing on HIV/AIDS information and promoting safe behaviour, since they reach the right target group (children and youth).

Ecological systems theory looks at the child's development within the context of the system of relationships that form his or her environment (Paquette & Ryan, 2001:1). The microsystem is the layer closest to the child and contains the structures with which the child has direct contact. These structures include family, school, neighbourhood, or childcare environments. Paquette and Ryan suggest that relationships have impact in two directions, namely both away from a child and toward the child. They cite an example whereby a child's parents may affect his or her behaviour, but also indicate that the child also affects the behaviour and beliefs of the parents.

2.3.4 Stigmatization

Children grieving for dying or dead parents are often stigmatised by society through association with AIDS (Alliance, 2003:4-8). The distress and social isolation experienced by these children, both before and after the death of their parent(s), is strongly exacerbated by the shame, fear, and rejection that often surrounds people affected by HIV and AIDS. Because of this stigma, children may be denied access to schooling and health care. Once a parent dies, children may also be denied their inheritance and property. Often children who have lost their parents to AIDS are assumed to be HIV positive themselves, adding to the likelihood that they will face discrimination at school and in their community, and thus damaging their future prospects. In this situation children may also be denied access to healthcare that they need. Sometimes this occurs because it is assumed that they are infected with HIV and their illnesses are untreatable.

It should be remembered that the process of losing parents to HIV/AIDS for the children often includes the pain and the shame of the stigma and the fear that the disease carries in most of the world's societies.

2.3.5 Family structures

In African countries that have already suffered long, severe epidemics, such as Botswana, Malawi and Zambia (United Nations Children's Fund's, 2007:7) AIDS is generating orphans so quickly that family structures can no longer cope. Traditional safety nets are unravelling as increasing numbers of adults die from HIV-related illnesses. Families and communities can barely fend for themselves, let alone take care of orphans. Typically, half of all people with HIV become infected before they are aged twenty-five years, developing AIDS and dying by the time they are thirty-five years, leaving behind a generation of children to be raised by their grandparents, other adult relatives or left on their own in child-headed households. In Vanderbijlpark and Vereeniging districts many young adults are dying daily, as confirmed by many funerals taking place even during the week. These young adults are leaving behind scores of orphans, who are likely to be taken care of family members, siblings and community members.

Traditional systems of taking care of children who lose their parents, for whatever reason, have been in place throughout Sub-Saharan Africa for generations. But HIV and AIDS are eroding such practices by creating larger numbers of orphans than have ever been known before. The demand for care and support is simply overwhelming in many areas. HIV reduces the caring capacity of families and communities by deepening poverty, through medical and funeral costs as well as the loss of labour.

The Cape Gateway (Cape Gateway, 2007:1), which is a government service aimed primarily at citizens of the Western Cape, provides information such as adoption, on local, provincial and national government. Cape Gateway defines adoption as a legal way for an adult single person or couple being unable to give birth to a child or wishing to bring another child into the family, to become the legal parent(s) of a child. Here the following categories of people are defined as legally able to adopt a child:

- A married couple can jointly adopt a child.

- Partners in a life-partnership (including same-sex partners) can adopt a child.
- A person who has married a natural parent of a child can adopt the child, that adoption of a step-child.

A single person (a widow or widower or an unmarried or divorced person) can adopt a child as a single person.

2.3.6 Manifestation of depression and anxiety

Ramsden (2002:23) provides the following depression and anxiety manifestations of AIDS orphans, which are that in general they:

- seem sad and without spirit;
- do not play with other children;
- do not appear interested in what is going on;
- seem weak and without energy;
- do not stand up straight or walk tall; and
- appear unwashed, with ingrained dirt.

Manifestations of the orphans of not having enough food are such as:

- reddish dry hair;
- dark patches of skin colour;
- thin – no fat under the skin, and bones showing; and
- one or two years smaller in size than others of their ages.

Orphans suffering from ill health, generally show the following signs, which are:

- coughing and very rapid breathing;
- diarrhoea;
- runny nose, sore eyes, pus from ears;
- swollen belly (especially in very young children and babies);
- sore around the eyes and mouth, or on the legs; and
- skin problems in general.

Constant behaviour demonstrated by orphans, shows a child in need and are the following:

- sadness, crying, and withdrawal;

- signs of fear and anxiety;
- aggression;
- clinging behaviour; and
- attention seeking, over-anxious to please, and forced happiness.

However, according to social constructivism theory, language is developed through interaction of children with their parents or caregivers, siblings and the society at large, thus depriving children an opportunity to interact this way may lead to deprivation from learning and development (Laurillard, 1993:89). Laurillard maintains that children may be deprived an opportunity to interact with different sectors of the community through natural as well as deliberate action by the society. Deliberate actions or man made causes in this instance, could be abuse by the caregiver by refusing her orphans to interact with other children or neighbours. In Vygotsky's theory, the development of language and articulation of ideas was central to learning and development (Vygotsky, 1978:5). In fact, McMahon argues that learners do not transfer knowledge from the external world into their memories, rather, they create interpretations of the world based upon their past experiences and their interactions in the world (McMahon, 1997:3). According to social constructivism, the learner being a member of a particular culture inherits historical developments and symbol systems, such as language; logic; and mathematical systems, and these are learned throughout the learner's life. It also stresses the importance of the nature of the learner's social interaction with knowledgeable members of the society, without which it is impossible to acquire social meaning of important symbol systems and learn how to utilise them (Gredler as quoted by Wikipedia, 2006:1).

These issues discussed above, implies that those who provide care, need to be looked into.

2.4 ISSUES RELATING TO PEOPLE WHO PROVIDE CARE TO AIDS ORPHANS

Issues relating to people who provide care for orphans whose parents died as a result of AIDS now receive attention in the next sections. Key points about carers of orphans and other vulnerable children are that:

- most orphans and other vulnerable children in developing countries are cared for by family members in the local community. These family members include surviving parents, grandparents, other adults and brothers/sisters. These people are a child's primary care givers;
- although men are often identified as a child's formal guardian, the burden of care falls mainly on women;
- primary care givers may receive support from a number of sources. These include community-based volunteers, professional staff and traditional healers; and
- caregivers may experience stress for a variety of reasons. In some situations, this stress gradually builds up until a person can no longer cope. Their physical and mental health, personal relationships and standards of care may all suffer. This is referred to as 'burnout'.

According to Gernholtz **and** Richter (2004:910), these caregivers are classified as informal caregivers who are categorised as grandparents, aunts, uncles, siblings or even sympathetic members of the community.

A study on caregiving has shown that community programmes that are developed to serve people affected by HIV/AIDS tend to rely on women as unpaid volunteers (UNFP, 2007:4). This is despite the fact that these women are as poor or poorer than the people they are assisting and yet receive neither stipends nor incentives. Furthermore, the Report of the Secretary-General's Task Force on Women, Girls and HIV/AIDS in South Africa points out that there is little recognition for volunteers, who may be subjected to exploitation and severe stress (UNFP, 2007:4). This may in turn lead to fewer people wanting to be involved in such community structures.

With the African countries having a high number of AIDS orphans as mentioned in section 2.3 above, it becomes necessary to have high quality care-giving for these children who become vulnerable to poverty, discrimination, sexual abuse, among many other social evils. In the early days of the AIDS orphans crisis, the most common form of care for orphans was orphanages, which were built by non-governmental organisations (Avert, 2007:4). However, given the scale of the problem, this type of response to this orphanage crisis was unsustainable because of the high cost of

maintaining a child in such an institution. The tendency, nowadays, is to have orphans cared for in family units through extended family networks, foster families and adoption (Avert, 2004:4). It is furthermore suggested that siblings should not be separated. Studies in Sub-Saharan Africa have repeatedly demonstrated that growing up in a family environment is more beneficial to a child than institutional care, which must be considered a temporary option or a last resort (Avert, 2004: 4).

Foster (2002:1) sees informal caregivers, which he calls 'extended family safety net', as the best traditional social security system. Many affected children are passing through this social security safety net because of the fact that the members within these safety nets have been responsible for providing:

- the protection of the vulnerable;
- the care of the poor and sick; and
- the transmission of social values.

Foster (2002:1) further points out that even when relatives died, the extended family support network would ensure that children are cared for, whether some of its members move into households to care for survivors, or whether orphans are moved out into one or more relatives' households.

In the extended family safety net, uncles and aunts form the first line of protection for vulnerable children. However, as this customary practice of orphan inheritance is weakened, it has been supplemented by greater responsibility on the part of grandparents or other relatives – almost always women. Those children who escape these two lines of protection end up in child-headed households, street or labour force (domestic work or other work).

Although the creation of child-headed households may be seen as evidence that the extended family safety net is unable to cope with situations created by HIV/AIDS, however, more evidence is surfacing that suggests that this might not be the case. Rather, child-headed households may be a mechanism used by extended families to cope with the situation. For example, many child-headed households live closer to their extended families, and are often visited by them as well as receiving limited amounts of

material support. Very often, younger children (under five years) are taken to live with the extended family, and the older ones and young people are kept together within child-headed households. It is well documented that female-headed households are among the poorest, and have little opportunity to escape from poverty (Rau, 2003: 22).

Various reasons are given for children and young people living in child-headed households rather than with extended families (Alliance, 2006:2). These reasons among others include:

- no relative could be identified to take care of them;
- it may reflect the wishes of the parent and/or the children;
- parents and children avoid risking loss of the family home and other property; and
- children and young people's wish of staying together.

International Social Services (ISS) and UNICEF outlined some of the advantages and disadvantages associated with this form of care (ISS/UNICEF, 2004:5). This form of care allows sibling groups to remain together and retain their family home. Some children see it as preferable to fostering, or being placed in a family where they may experience discrimination, and all fear immediate or subsequent separation from siblings in such alternative situations. On the other hand, child-headed households face difficulties in earning a sufficient livelihood, and are likely to lack experience in dealing with problems, and are especially vulnerable to abuse and exploitation.

The ISS/UNICEF Working paper (2006:3) provides a list of issues for which internationally agreed guidelines or minimum standards do not exist and are needed, almost all of which are relevant in the context of HIV/AIDS. Those issues, which are considered of absolute importance in this regard, include:

- services to be provided for maintaining children in safety with their parents wherever possible;
- conditions to be met when children are to be removed from their parental care;

- processes and mechanisms enabling the children (and, where applicable, their parents) concerned to have a real say in the care option chosen, and to be consulted regularly throughout the period in which out-of-home care is provided;
- permanency planning;
- protection in informal care situations;
- selection, training, monitoring and support for foster carers;
- recourse to, and conditions in, residential care; and
- responses to child-headed households.

The UNICEF/ISS recommends that both the international and national standards and guidelines be advocated in order to respond to the specific concerns, and also explicitly address the following:

- the importance of provision to prevent separation. In the case of parents or children living with HIV – and other chronic diseases – access to health care and related services can prolong lives and make it possible for parents to remain with their children, and siblings to remain together;
- mechanisms for supporting and monitoring kinship care as well as other forms of informal foster care which can be met by a majority of countries and which help ensure greater protection for children living in such care arrangements;
- care options and legal mechanisms to ensure appropriate support for abandoned children, and prevent unneeded separation of children from their peers or other discriminatory treatment;
- guidance on appropriate use (if any) of medical considerations in the determination to remove children from care or to isolate them with their care environment;
- guidance on appropriate use of different care options, including innovative options for older children, such as child-headed households and other supported, independent living arrangements; and
- standards relating to inheritance and succession rights as an integral part of permanency planning.

Foster (2002:4) observed that although these vulnerable children slip through the extended family safety net, the community visiting these AIDS-affected child-headed households is a major element in community solidarity. Most of these visits are conducted by village women and consist of brief social visits to ensure the well-being of their neighbours. Even in this study, most of the cases identified of child-headed households have been brought to our attention through neighbours who were concerned about the well-being of these children, but could not help due to poverty.

Marcus (2004:5), the head of psychosocial services at Hospice, one of the South Africa's main palliative-care facilities, commented in the country's major newspapers that children in South Africa very seldom reach formalised counselling. However, there was a growing realisation among people at the forefront of the fight against AIDS, for example caregivers, social workers and educators – those children who had been affected by the pandemic needed more than just shelter, food and clothing. Children need to talk about their feelings as opposed to these feelings just being absorbed into their everyday lives. van Eyssen (2004:3) wrote in her weekly column of *The Star* newspaper about the *Magical AIDS Journey*, a board game designed to help children affected with HIV/AIDS come to terms with the impact of the disease on their lives.

Ebersöhn and Eloff (2002:77) published an article on the complexities of HIV/AIDS to the coping of traumatised South African children. In their study, they found that HIV/AIDS constitutes a chronic stressor in the lives of many South African children. For example, children live with the stress of being without the familiar care of a mother, have to bear hardship and responsibility on account of parents' unemployment, face being stigmatised by peers and treated as social outcasts, are burdened by grief for lost family members, lost homes or lost opportunities. They further assert that these traumatised children are prone to feelings of inadequacy and depression and may further suffer Post Traumatic Stress Disorder. Ebersöhn and Eloff (2002:77) highlighted the following effects of HIV/AIDS to contextualise the predicament of these vulnerable children:

- demographic effects - They estimated that sixty one percent of 16.3 million children, which is half of South Africa's 38.8 million population, live in poverty. It

is estimated that in sub-Saharan Africa, children under the age of five are expected to outnumber adults over the age of 44 of HIV/AIDS;

- health effects - Children living in infected communities suffer from poor nutrition and ill health, and show signs of failure to thrive. Furthermore, children's nutritional status suffers in rural areas that are dependent on household labour for subsistence agricultural production. Where social services, hospital and home-care systems are stretched or absent, vulnerable children have inadequate access to health care;
- family-life effects - As young or middle-aged fathers and mothers die, grandparents take full-time care of young children and sometimes these children have to assume unfamiliar adult roles at home for which they are ill-prepared. Sometimes they even become primary caretakers of their infected elders, assuming adult responsibilities, washing, cooking for and feeding sick elders and young siblings;
- welfare effects - Economically children and their families are hard hit. For example, on account of poor health productive members of the family are often unable to continue work. Even when caregivers attempt to protect children by not discussing economic difficulties with them, the children are attuned to their emotional environment and readily adopt the anxiety, fear and frustration that accompany financial strain;
- educational effects - A marked decline in school attendance already characterises the South African education landscape. Affected and/or infected children shy away from disclosure because of illness, morbidity and death, fear of discovery and shaming at school, increased demands for child labour, including caring for sick relatives (both in and outside home), and inability to pay school fees;
- psychosocial effects - Children's psychosocial distress and trauma is often not as visible as that of their health, education and economic needs. The psychosocial challenges children face include coping with grief, loss of identity (self-, family- and cultural identity), coping with shame, stigmatisation and fear of abandonment, rejection, and death; and
- orphanhood effects - It is estimated that on current mortality trends, orphans will comprise nine to twelve percent of South Africa's total population by 2015.

These orphans may live in child-headed households with older siblings looking after younger ones, thus assuming parenting roles that they are ill-prepared for, while others are taken care of by communities, some are placed in institutions, and still others lose all contact with carers and become street children.

Outside of school, HIV/AIDS orphans may likely miss out on valuable life-skills and practical knowledge that would have been passed on them by their parents (Avert, 2005: 3). Salaam (2005:2) argues that without this knowledge and basic school education, children may be more likely to face social, economic and health problems as they grow up.

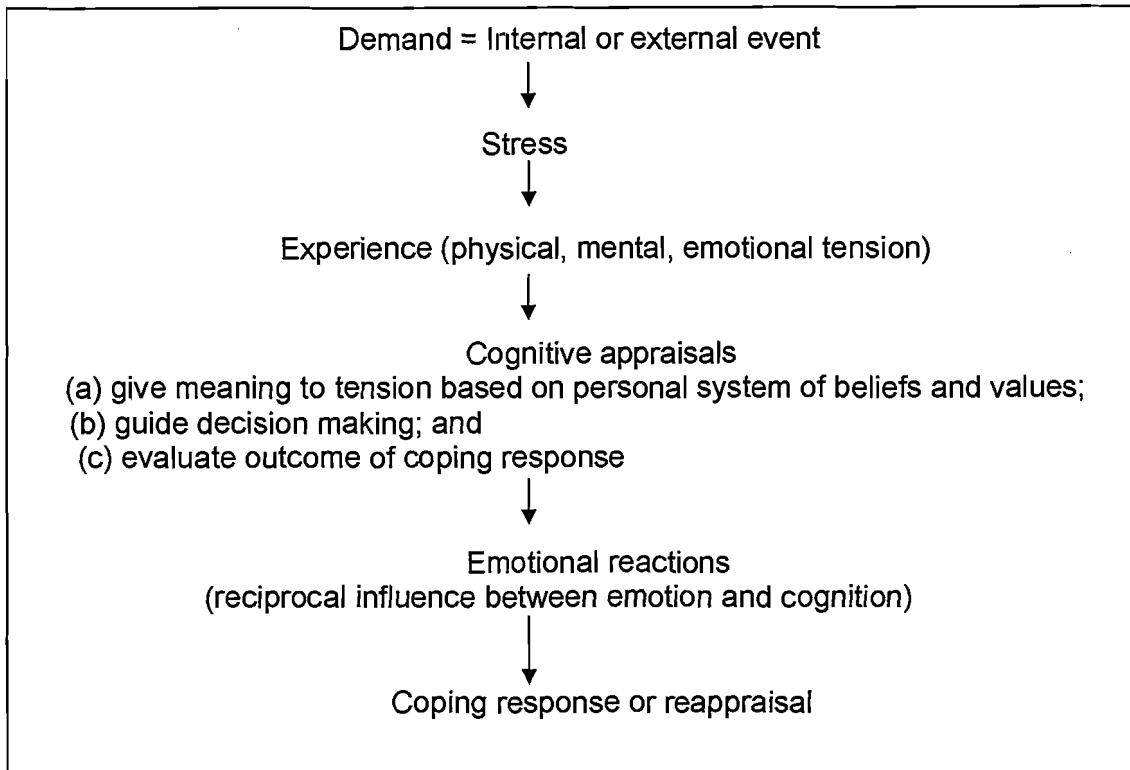
The ILO report provided the following evidence of the linkage between HIV/AIDS and child labour, which appeared in all the rapid assessments (RAs): children who are from households affected by HIV/AIDS often must enter the labour market because families cannot meet their basic needs without contributions from the children (Rau, 2003:32). The report argues that as a result, children may be subjected to harsh and exploitative conditions and sexual abuse. The report suggests that the effects occur under the following conditions:

- Children are withdrawn from school to reduce family expenses, and then seek work;
- Children are placed with extended family members, but are expected to work;
- Children flee new arrangements because of depression, neglect or exploitation, and have to work.

Schools should be enabled to learn how to play an active role in looking for HIV affected and infected children in their communities, and persuading them, or their caregivers or guardians to come back and remain in school (Wijngaard & Shaeffer, 2004).

According to Resilience Theory, children should have access to resources (internal and external) to cope effectively, so as to change what they can or make the best choices regarding things they cannot change (Ebersöhn, & Eloff, 2002:77).

Figure 2.2: The universal stages of transactional coping process



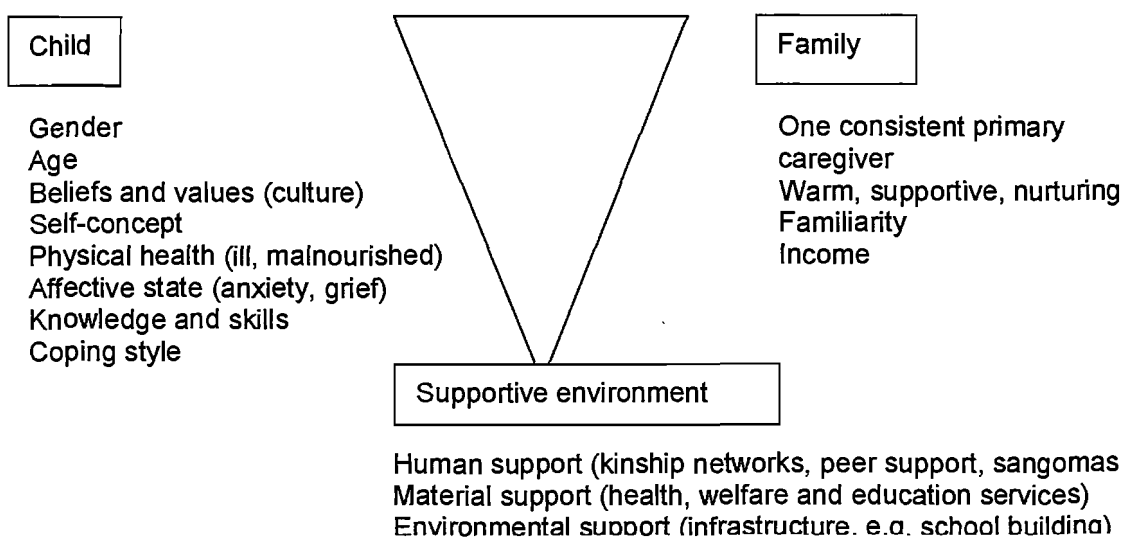
Source: (Zitlin & Williamson as quoted by Ebersöhn & Eloff, 2002:78)

Figure 2.2 illustrates the universal stages of transactional coping process. According to the transactional coping process the environment makes constant demands on the individual. The individual experiences these demands as stress (anxiety, tension). The individual has to decide how to manage the stress. The outcome of decision-making is either a coping response or reappraisal. For example, a child's infection may become less threatening to his/her educators when the educators acquire knowledge that encourages them to believe his/her presence is not harmful to others.

Furthermore, a certain coping response will influence the child's environment, and may in turn present new demands on the individual or alleviate the stress. The following example illustrates the reciprocity in the transactional coping process. An orphaned girl may decide to cope with trauma by having a sexual relationship with an educator. Her choice increases her susceptibility to infection, yet provides her with lunch money and assistance in passing grades. Her stigmatised family, seeking social acceptance, may strengthen her acquaintance with an admired community figure. If she becomes

pregnant, or infected, or both, she may be abandoned by the educator, which adds her personal trauma to the distress already experienced by the family.

Figure 2.3: Protective factors that act as buffer to the effects of trauma on children



Source: (Ebersöhn & Eloff, 2002:79)

Figure 2.3 illustrates the interrelatedness between protective factors that might buffer the effects of trauma on a child, and these protective factors become crucial when children are under threat of getting AIDS. Ebersöhn and Eloff (2002:80) argue that in times of crises children revert to primary emotional coping strategies, where their dependence on adult support to assist them in coping is critical.

Table 2.3: Coping stages of traumatised children

Stage One	Stage Two (similar to stage one, but less intense)
Initial shock	Less crippling emotional state
High level of distress (anxiety, helplessness)	- Poor solutions may be maintained because they lack other options - Support from adults means that fears can be voiced and options explored

Source: (Ebersöhn & Eloff, 2002:80)

Table 2.3 illustrates the integration of the essence of the transactional process (Figure 2.2) with protective factors (Figure 2.3), where the emphasis is on emotion, basic solutions and support from adult caregivers for children's effective coping.

In the absence of such support (child-headed households, abandoned orphans, street children) children's repeated experiences of helplessness will result in despair at their lack of control. Experiencing that they consistently cope ineffectively may generate an unwillingness to try managing similar situations, may bring about additional stress and create feelings of inadequacy, as will be investigated in this study.

HIV/AIDS triggers multiple anxieties in a child. For example, stressors may be environmental demands such as exclusion from school, or having to find money for a funeral. Internal challenges may be bewilderment at drastic changes in family circumstances, profound grief at the loss of a mother or father. The challenges could be the physical changes of a weakening body. A child may experience anguish trying to find out what is happening to her/him when she/he is removed from a familiar community and placed in an institutional care.

Connard and Novick (2001:1) suggest that the "goodness of fit" model could be useful for understanding how to support and strengthen families. They purport that stress builds when the resources and coping skills of a family are inadequate to meet the demands and expectations of the social environment. They further suggest that family stress levels are a predictor of "rotten outcomes" for children. According to Family-Centred Approach (Connard & Novick, 2001:1), one part of the system cannot be understood in isolation from the other parts. For example, children cannot be understood outside the context of their families (Connard & Novick, 2001:2). The theory states that every member of a system influences every other member in a circular chain reaction. Thus a family system is constantly changing as children develop; hence it is almost impossible to know for certain the cause of behaviour. Krauss and Jacobs (Krauss & Jacobs as quoted by Connard & Novick, 2001:3) view all behaviour as interpersonal messages that contains both factual and relationship information (Krauss & Jacobs quoted by Connard & Novick, 2001:4). This suggests that an orphan, who lies about her caregiver physically abusing another orphan, and even signing a

declaration at the police station, may be trying to pass on a personal message of a relationship that has turned sour to her caregiver.

Fredriksson **and** Kanabus (2005:3-4) regarded prevention and care as a way forward for supporting children orphaned by HIV/AIDS. They further proposed the following as intervention mechanism to support children orphaned by HIV/AIDS:

- care in the Extended Family - Most people are now beginning to realise and convinced that orphans should be cared for in family units through extended family networks, foster families and adoption. Furthermore, siblings should not be separated. This perception was brought about by the fact that orphanages built mainly by non-governmental organisations provided an unsustainable response, due to the magnitude of the scale of the problem;
- support for Communities - The extended family can only serve as part of the solution to mass orphanhood if adequately supported by the state, community and other sectors. Orphans need to be accepted as part of the community and to have access to essential services such as health care and education. This implies that existing services have to be improved and reducing the stigma surrounding children affected by AIDS so they are not stigmatised and denied the services they need;
- keeping Children in School - Keeping children at school provides education that can work as a safety net in the child's life. Schooling can also break the cycle of poverty. Orphans may be the first to be denied education when extended families cannot afford to educate all the children of the household;
- empowerment for Children - Children can be empowered by regarding them as active members of a community rather than as victims. Since many of these children already function as heads of households and as caregivers, they are a vital part of the solution and thus should be supported in planning and carrying out efforts to lessen the impact of HIV/AIDS in their families and communities;
- protection for the Legal and Human Rights of Orphans - Many communities should be made aware of the importance of writing a will, so as to protect the inheritance rights of children and to prevent land and property grabbing, i.e. an

adult attempting to rob orphans of their property once the children have no parents to protect their rights; and

- meeting Emotional Needs: Many orphans will often have many physical needs such as nutrition and health care, and these can often appear to be the most urgent. They will also have significant emotional needs as well as the sickness and death of a parent, which is clearly a major trauma for any child.

Links **and** Masson (2004:127) highlighted the adverse effects of the impact of HIV/AIDS on grandparents and other relatives caring for HIV/AIDS affected children, in the USA. They noted that parental absence or incapacity resulting from HIV/AIDS is one of the reasons for an increase in non-parent relatives raising children. Research on grandmothers as caregivers has documented adverse psychological functioning that results from care giving, such as distress, depression, anger, resentment, and parenting stress. Grandparents caring for their grandchildren also reported reduced level of physical functioning or physical limitations that may affect their quality of life and caregiving capacity.

Ogunmefun **and** Schaltz (2006:2) argue that as more young men and women are falling prey to the HIV/AIDS epidemic, older women are more likely to be asked to provide care for the ill and orphans left behind (Ogunmefun & Schaltz, 2006:2). Ogunmefun and Schaltz further maintain that as caregivers, they incur some losses, which include income (earnings forgone as they stay at home to give care), savings, wealth assets, and health (due to stress and strain). Other losses associated with care are increases in expenditure on health care, funeral costs and payment of debts, which strain already thin household budgets that must cover food, housing, and educational expenses (Ogunmefun & Schaltz, 2006:2).

Albertyn (2003:595) argues that the HIV/AIDS epidemic is likely to undermine the efforts being made by the government to redress the inequalities created by apartheid by forcing the elderly to use economic resources meant to alleviate their own poverty, to assist the needs of their families. This study has shown that caregivers, who are also pensioners, are using their old-age grants to supplement the foster grants given for orphans. In fact, Ogunmefun and Schaltz's data had shown that female pensioners were using their grants to reduce financial burdens associated with adult illness and

death, especially HIV/AIDS related morbidity and mortality, rather than alleviating their own poverty. This is supported by a joint report by UNAIDS, UNFPA and NUNIFEM, which has shown that women's role in the care economy intensifies their poverty and insecurity since a large proportion of an already meagre income is used to support their care giving and purchasing of items such as water, gloves and medicine or paying for funerals. This report further suggested that the increased workload of family income and deepening poverty make women more dependent on others and exacerbate gender inequalities.

In other studies, grandparents often report that despite the burden, caregiving is rewarding; they express relief and happiness at being able to provide a good home for their grandchildren (Burton, 1992:7; Minkler, Roe & Price, 1992:4). In another study conducted in India, D'Cruz (2005:90-92) attests to that, by asserting that the family-based care is becoming more important across the globe. D'Cruz noted that home and community-based care is now widely preferred, and acknowledges that cutbacks in social expenditure force families into these modes even when institutional care would have been their first choice.

The UNAIDS agency has learnt very important lessons, which is recognition that the extended family, with the support of the surrounding community, are the best people to care for orphans and probably the only viable and sustainable solution, especially in areas of mass orphanhood (Zaba, Whiteside & Boerma, 2004:66). In another study conducted in Uganda, the main challenge which kept unfolding during the study, and which is consistent with studies conducted in sub-Saharan African countries is the fact that grandmothers, who form the majority of caregivers, are in most cases incapable of providing adequately for orphaned children. Often grandmothers would desire to offer the best support for their grand children. However, monetary and other constraints do not allow them to live up to this expectation.

Other problems experienced by the caregivers were "role strain" and "identity". For example, many grandmothers had problems whether they should see themselves as mothers (as they are normally referred to by grand children) or grandmothers. They also find it difficult having to care for their grand children under conditions of increasing

personal impoverishment, associated with problems such as depression for both generations.

Shilubana **and** Kok (2006:101-107) conducted a study to investigate the performance of without adult care at home. Most of the learners who succeeded at school cited the following coping mechanisms, which were that:

- all learners interviewed highlighted some form of support that they get from either relatives staying in the same community, friends, or educators, especially the guidance educators at the school;
- the feeding schemes and the food parcels organised by the school;
- some relied mainly on peers for completion of homework; and
- others relied on study groups.

The study also revealed that there were some challenges that learners highlighted, including:

- insufficient money, which contributed to shortages in food, electricity cuts, lack of school uniforms and other school requirements;
- inadequate basic necessities;
- lack of security;
- siblings fights; and
- lack of medical care.

Support mechanisms provided by the school, highlighted by the study, were:

- bread and milk provided to the affected learners;
- motivational talks and advise organised for learners;
- visits of staff from local clinic on health matters; and
- old clothes and food parcels were organised for distribution to needy learners.

Pharaoh **and** Weiss (2005:1) investigated the impact of HIV/AIDS on orphans, crime, and stability. They found that in much of the developing world, particularly in Africa,

AIDS is undermining education and health systems, economic growth, micro-enterprises, policing and military capabilities, political legitimacy, family structures, and overall social cohesion. The authors also argue that when growing up without parents, and children badly supervised by relatives and welfare organisations means that, this growing pool of orphans will be at greater than average risk of engaging in criminal activity. For example, without caring adults to protect them, orphaned children can be manipulated into doing almost anything.

The older and younger ages of many caregivers make them particularly vulnerable to physical strains of care-giving, which manifest in the form of stress and burnout. Care givers may experience stress for a variety of reasons. In some situations, this stress gradually builds up until they can no longer cope. Their physical and mental health, personal relationships and standards of care may all suffer. This is referred to as 'burnout'. Primary care givers may experience stress and burnout, as well as volunteers and professional staff, and signs of stress include:

- physical symptoms, such as inability to sleep and bowel disturbances;
- emotional problems including feelings of inadequacy, helplessness and guilt;
- withdrawing from other people;
- reduced quality of care; and
- worsening relationships with other people.

Stress in caregivers can be caused by a number of factors including:

- poverty and its effects, including lack of resources to meet survival needs of both the child and carer. This includes lack of food and medicines;
- interpersonal and family conflict. This is common within families affected by HIV/AIDS because the virus spreads mainly through sex. This often leads to people being blamed for 'bringing the virus into' the family;
- isolation and fear for the future;
- excessive workload;
- stigma and discrimination relating to HIV/AIDS;
- excessive personal involvement in issues relating to the child; and

- poor organizational arrangements. This applies particularly to secondary care givers. issues include lacking a voice in the way things are done, inadequate support and lack of clarity over roles.

On the other hand, stress and burnout can be managed by developing personal coping mechanisms and organisational strategies. Religious faith may be important as part of personal coping mechanisms. Organisational strategies include:

- recognising that caring is stressful and that stress and burnout are complex;
- ways of dealing with problems that carers can not deal with;
- finding ways of showing that carers are valued;
- providing carers with training;
- relieving poverty and ensuring that activities are reliably funded;
- effective stress management measures including regular time off, realistic workload, team meetings and participation in decision-making;

A similar study conducted by Burgos, Hernandez-Reif, Mendoza, Castillo **and** Shorposner (2007:2) on Dominican children behaviour, found that caregivers of HIV positive children face many challenges related to both physical demands and emotional well-being. They assert that caregivers of children with HIV face many challenges such as depression, fatigue and exhaustion, similar to problems of those who care for children with life-threatening diseases. They purport that diminished stamina and physical demands of a HIV positive child leave many caregivers without adequate time for self-care and counselling. Burgos et al. maintain that stress of raising HIV-infected children may precipitate or exacerbate chronic psychological conditions in caregivers, and thus impacting on their perception of the child's behaviour. Furthermore, HIV is associated with additional stressors, such as social stigma and isolation that may limit caregivers' willingness to seek assistance from formal agencies, for them or their families.

Ebersöhn **and** Eloff (2002:77) highlighted some of the complexities of HIV/AIDS to the coping of traumatised South African children. They established that HIV/AIDS constitutes a chronic stressor in the lives of many South African children. For example, the authors argue that some of the chronic stressors include children living with the stress of being without the familiar care of a mother, having to bear hardship and

responsibility on account of parents' unemployment, facing being stigmatised by peers and treated as social outcasts. Furthermore, these children are burdened by grief for lost family members, lost homes or lost opportunities. They further assert that these traumatised children are prone to feelings of inadequacy and depression and may further suffer Post Traumatic Stress Disorder.

In his opening address to the conference on orphans and other children made vulnerable by HIV and AIDS, the Minister of Social Development, Dr Zola Skweyiya emphasised that the protection of the rights of orphans and other children made vulnerable by HIV/AIDS and other social ills requires the involvement of government and other sectors, including faith-based organisations, community-based organisations, business sector, labour, donor and development agencies (SARPN, October 2007:1).

2.5 THE NATURE OF CARE NEEDED FOR AIDS ORPHANS

The nature of care needed for AIDS orphans can take the following forms, which are social grants; home- and community-based care and support programmes; services for children; partnerships; United Nations Children's Fund; Save the Children Fund; and faith-based organisations and the business sector, and are discussed in the sections that follow:

2.5.1 Social grants

In Thailand (Avert, 2005:6), the wide availability of basic government health insurance helps moderate the economic impact on families. Parents reported that, in three-fifths of cases, insurance helped pay health care costs, and more than one-half of these said it helped very much. Such a situation is far less probable, however, in the countries hardest hit by the epidemic, especially much poorer ones in Africa. The Thai insurance also did not cover antiretroviral treatment. Expenses to be borne by parents in Thailand and other developing countries may increase sharply as awareness and availability of antiretroviral treatment spreads. Features of the Thai context may also have moderated the amount of stigma experienced by AIDS parents and their infected children. Community reaction is variable, but generally much more sympathetic and supportive than typical media descriptions and accounts given by advocacy groups imply. The WHO study in Zimbabwe (Fischer & Mutikani, 1998:4) also indicates that only a minority

of older-age caregivers reported experiencing stigma. Clearly, more research is needed on the way AIDS affects the older parents in a wide variety of social, economic, and epidemiological settings.

In order to take care of AIDS orphans, Ramsden (2002:32) suggests the following social grants provided by the South African government, which are:

- child support grant – given for children up until 7 years of age;
- foster care grant – for children up until 18 years of age;
- care dependency grant – for parent or foster-parent of a severely mentally or physically disabled child who needs constant care;
- social relief of distress grant – meant as a temporary help for persons who are vulnerable (at risk) and those who are destitute and so poor that they have nothing to meet their needs;
- free health care for children under 6 years; and
- exemption from school fees.

In terms of SASA (84/1996) children of 7 – 15 yrs of age are exempted from school fees. According to the Bulletin of the Department of Social Development, by March 2006, social grants were being paid to 11 million South Africans (Social Development Bulletin, 2006:510). The number of people benefited are categorised as follows:

- foster care grants (300 119);
- care dependency grants (91 604);
- war veterans' grants (2 858);
- old-age grants (2 131 820);
- disability grants (1 312 726); and
- child support grants (6 961 046).

From this information, it can be seen that child support grants made up the largest social grant. Old-age grant contributed as the second largest social grant.

Table 2.4: Amounts of grants per month in South Africa as at 1 April 2006

Grant type	Amount (Rand) per person
Old-age grant	820
Disability grant	820
War veterans' grant	758
Foster care grant	590
Care dependency grant	820
Child support grant	190
Grant-in-aid	170

Source: (Social Development Bulletin, 2006:512)

Table 2.4 shows the amounts of social grants per month as at 1 April 2006, of different types of social grants available in South Africa. It is clear from this table that the amounts of the old-age, foster care and child support grants are insubstantial compared to the economic demands of caregivers.

The Social Development Department, in addition to providing social assistance, is also managing the Poverty-Relief Programme. The department has contracted the Independent Development Trust (IDC) to provide implementation support of these projects.

2.5.2 Home- and Community-Based Care and Support Programme

The department of Social Development in South Africa stated that about R4,2 billion was expected to be spent in 2006/07 on social-sector employment programmes, which include home- and community-based community care, community health workers and social-development partnerships with non-governmental organisations, NGOs (Social Development Bulletin, 2006:512). The department emphasised that care of child-headed households, strengthening of HIV and AIDS programmes, and appropriate management of children in conflict with the law are among the social-service priorities. The Home-and Community-Based Care and Support Programme is aimed at teaching life skills to children and the youth. It also provides voluntary testing and counselling services and a range of care and support services, focusing on families and on children orphaned by AIDS-related deaths of their parents.

2.5.3 Services for children

These services are provided through “drop-in” centres that have been identified by each province, and are contracted to provide cooked meals to identified beneficiaries (Social Development Bulletin, 2006:512). The beneficiaries are classified as people who are unable to cook for themselves, for example, child-headed households.

2.5.4 Partnerships

The Social Development Department has, since 2000, strengthened its partnerships with national and international organisations involved in the fight against HIV and AIDS (Social Development Bulletin, 2006:513). The following are some of the organisations that the department is working in collaboration with:

- **United Nations Children’s Fund (Unicef)** - Unicef, has conducted various studies on caring for vulnerable children and children orphaned through HIV/AIDS (Social Development Bulletin, 2006:513). Unicef has also conducted studies on the cost-effectiveness of several models of care for vulnerable children. The Department of Social Development has implanted the results of these studies in its design of programmes for children. Unicef has further indicated interest in providing further support to the department in fast-tracking the Home- and Community-Based Care and Support Programmes.
- **Save the Children Fund** - This organisation provides secretariat and other assistance to the National AIDS Children’s Task Team (NACTT) and has undertaken research on abused children and children affected by HIV/AIDS (Social Development Bulletin, 2006:513). It has also compiled a directory of social services and children’s organisations.
- **Faith-Based Organisations (FBOs) and the Business Sector** -The department has strengthened its partnership with churches and other FBOs, the business sector, volunteer organisations, and individuals, to assist with poverty-relief, HIV/AIDS and social-grant registration programmes (Social Development Bulletin, 2006:513).

In a study conducted by Sengendon **and** Nambi (1997:105) in rural Mozambique, they found that carers of orphans showed more depression and less social support.

A study conducted in Namibia has uncovered that the majority of households caring for orphaned children were already suffering financial hardships (Anon., 2000:3). This study suggests that the care giving household was not able to rely on financial support from the dying parent(s) because either the family was already in poverty, or because they used their resources treating the dying parent(s). It is purported that this leads to the inability of the extended family system to provide orphans with basic requirements such as shelter, food, medical care, education, love and support (SARPN, 2005:1). Stigma, discrimination and poverty are also identified as contributors that lead to orphans being denied or discouraged from accessing basic services, such as health care, education and social services. Caregivers have great difficulty in having to disclose to orphans the source of their parent(s) death, or even the orphan's HIV status. In fact, Cluver and Gardner (2006:2) reported that caregivers suffered psychological health themselves. They also mentioned that South African orphans reported that stigma and secrecy surrounding AIDS, causes social isolation, bullying, shame, and a lack of opportunity to openly discuss their loss.

2.5.5 Inclusion

One of the mechanisms used in addressing stigmatisation and discrimination of children orphaned by HIV/AIDS related diseases in South African schools is 'inclusion'. Inclusion is seen as a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning cultures and communities, and reducing exclusion within and from the education system. Inclusive education aims at providing appropriate responses to the broad spectrum of children's learning needs. It has already been highlighted that many countries are faced with the problem of having to deal with vulnerable and disadvantaged children. Among some of these vulnerable and disadvantaged orphaned children, the following categories can be identified:

- poor: those who can not afford to pay school fees, and forced to join the labour force in order to take care of their siblings, or family members, as well as coping with malnutrition;
- street children - they rarely attend school regularly and if they do they usually drop out early; and
- children living in remote and rural areas or constantly moving - they live in places with lack of infrastructure or they are not registered as living in one place so they

do not have the means to enrol at school. Schools may be used as a vehicle to offer support to caregivers of orphaned children.

HIV/AIDS is also associated with 'taboo' subjects such as sex, death and blood, and with behaviours such as commercial sex, drug use and homosexuality (Alliance, 2003:3). This leads many people to stigmatise and discriminate against anyone with HIV or affected by HIV. Children are especially sensitive to the damaging psychological effects of stigma. Stigmatisation and discrimination create and reinforce the social isolation of those affected by the epidemic. Orphans, vulnerable children and their caregivers are often unaware of their rights and the laws intended to protect them from discrimination. However, if they are aware of these rights, they fail to demand better treatment from their caregivers or community.

Clasen (2004:1) considers one's integration into society as being a critical aspect of good citizenship, which he argues should be classified among the most fundamental rights available to all, for example, food; shelter; education; and health care. To date, inclusion remains a controversial concept in education because it relates to educational and social values, as well as to our sense of individual worth. Inclusion is a term that expresses commitment to educate each child, to the maximum extent appropriate, in the school and classroom he or she would otherwise attend. Inclusion is a process by which schools; local education authorities and others develop their cultures, policies and practices to include all children and young people (Smith, 2002:7). Its main concern is to overcome barriers to access and participation in education, by bringing the support services to the child (rather than moving the child to the services) and requires only that the child will benefit from being in the class (rather than having to keep up with the other learners).

Inclusive education means that all students in a school, regardless of their strengths or weaknesses in any area, become part of the school. Both the Advocacy Board at the Centre on Human Policy, at the Syracuse University in New York and the School of Educational Sciences at the Vaal campus of the University of Potchefstroom (Smith, 2002:5), maintain that inclusion involves, among others:

- providing all students enhanced opportunities to learn from each other's contributions;

- providing necessary services within the regular schools;
- teaching all children to understand and accept human differences;
- seeing the difference between students as a resource to strengthen learning, rather than as a problem to overcome;
- reforming the cultures, policies and practices in schools so that they respond to the diversity of students in the neighbourhood;
- acknowledging the right of students to an education in their neighbourhood; and
- promoting mutually sustaining relationships between schools and communities.

It is argued that discussions about inclusion should address several important questions, among which are:

- Do we value children equally?
- Is anyone more or less valuable?
- What is meant by inclusion?
- Are there some children for whom “inclusion” is inappropriate?

There are advocates on both sides of the issue. Before any recommendations can be made towards effective implementation of inclusion, several factors will be presented.

The legal enforcement of segregation on the grounds of disability, learning difficulty or emotional need is said to be against international human rights agreements including the UNESCO Salamanca Statement and Framework for Action (Spain, 1994), which was later restated at the World Education Forum in Dakar (Senegal, 2000); the UN Standard Rules on Equalisation of Opportunities for Persons with Disabilities proclaiming participation and equality for all (1993); and the UN Convention on the Rights of the Child (1989):

- caregivers of orphans and vulnerable children are often very poor and receive less attention from health workers. They are often treated badly, shouted at and handled without proper care; and
- in order to protect them from further opportunistic infections, children with AIDS may be isolated from others in labelled wards or clinics; for example, AIDS clinics. While the intentions are good, this separation is stigmatising for children and their caregivers.

As a result of above issues, the following intervention strategy is proposed (Alliance, 2003: 8):

- promote a supportive legal framework - advocate for laws and policies that make stigma and discrimination illegal;
- promote a supportive community environment - information can help to reduce stigma. Ensure that communities are aware of laws and policies that support the rights of children, and they have basic knowledge about HIV/AIDS and the modes of transmission;
- promote psychosocial support for children affected and infected by HIV;
- target influential community members such as educators, health workers, traditional leaders, religious leaders and organisations by encouraging them to play an effective role;
- promote children's platforms where their voices can be heard and they can express themselves freely;
- provide necessary training for educators and help other school children to become aware of how children affected by HIV might feel;
- target support to vulnerable households and children – bearing in mind that where the majority of families are living in poverty, targeting assistance to children affected by HIV/AIDS can cause resentment and increase stigmatisation of these children;
- help children and caregivers to cope with stigma and discrimination - strength the ability in terms of skills and resources (capacity) of children and their caregivers to challenge stigma and discrimination;
- enable children to protect themselves from HIV infection - provide children with information, skills and the means to protect themselves; and
- take a multi-sectoral approach to meet the needs of socially excluded children.

2.6 CARING AS THE WAY TO HELP AIDS ORPHANS

Caring is one way to help AIDS orphans (Alliance, 2003:9). Care must be provided for those children who are already orphaned. This section is devoted to issues around the care of AIDS orphans in Africa. The situation of AIDS orphans is generally generated by adult deaths.

Most orphans and other vulnerable children in developing countries are cared for by family members in the local community. These family members include surviving parents, grandparents, other adults and brothers/sisters. These people are a child's primary care givers.

A study in Uganda (Avert, 2005:3) showed that orphans received care from a surviving parent in fifty per cent of situations. Other carers were grandparents (35%), aunts/uncles (11%) and brothers/sisters (3%). Most of the brothers and sisters providing care were aged over eighteen years of age but there was one situation where care was being provided by a child under the age of eighteen years.

Although many children are cared for by surviving parents, this is not automatically the case when one parent dies. Reasons why this might not be the case include:

- cultural practices which lead to children being 'inherited' by one side of the family (often the father's) rather than by the surviving parent (usually the mother);
- the surviving parent remarrying and the new partner being unwilling to take on responsibility for the children. This is strongly influenced by cultural norms and practices;
- better economic prospects for the child with the extended family; and
- the surviving parent being unable to care for the children. A common reason for this relates to the parent's need to work.

Although men are often identified as a child's formal guardian, the burden of care falls mainly on women. Primary care givers may receive support in different ways, which include the ones that are discussed below (Avert, 2005:5).

2.6.1 Support for carers

As said above, in the early days of the AIDS orphans' crises, there was a rush by well meaning non-governmental organisations to build orphanages. Given the scale of the problem, though, this response was unsustainable, as the cost of maintaining a child in such an institution is much greater than other forms of care. Most people now believe that orphans should be cared for in family units through extended family networks, foster families and adoption, and that siblings should not be separated. Studies in Sub-Saharan Africa have repeatedly demonstrated that growing up in a family environment

is more beneficial to a child than institutional care, which should be considered a temporary option or a last resort.

Ultimately, though, the extended family can only serve as part of the solution to mass orphanhood if adequately supported by the state and the community, as well as other sectors of society.

The community needs to be supportive of children when they are orphaned, making sure that they are accepted and have access to essential services, such as health care and education. This means improving existing services and reducing the stigma surrounding children affected by AIDS so that they do not face discrimination when trying to access these services.

According to Paquette and Ryan (2001:1), communities must provide parents with access to people with similar concerns that can function as resources and emotional support. In fact, community support is a cornerstone of a "Family-Centred Approach" theory, whose key components are the following (Connard & Novick, 2001:3):

- Creating partnerships and helping relationships: families are supported and child development is enhanced through helping and partnership relationships;
- Building the community environment: families gain information, resources and support through their connections to the community environment;

Linking families and community support: participation, two-way communication, and advocacy strengthen both the community support network and family functioning.

2.6.2 Keeping children in school

Schools can play a crucial role in improving the prospects of AIDS orphans and securing their future. A good school education can give children a higher self-esteem, better job prospects and economic independence. As well as lifting children out of poverty, such an education can also give children a better understanding of HIV and AIDS, decreasing the risk that they will become infected. Schools can also offer benefits to AIDS orphans outside of education, such as emotional support and care.

Unfortunately orphans may be the first to be denied education when extended families

cannot afford to educate all the children of the household. This will lead to an indictment against SASA (84/1996) in the case where such orphans are between 7 – 15 yrs of age.

2.6.3 Empowerment for children

If AIDS orphans are as active members of the community rather than just victims, their lives can be given purpose and human dignity. Many children already function as heads of households and as caregivers. They are a vital part of the solution and should be supported in planning and carrying out efforts to lessen the impact of AIDS in their families and communities.

2.6.4 Protection for the legal and human rights of orphans

Much can be done to ensure the legal and human rights of AIDS orphans. Many communities are now writing wills to protect the inheritance rights of children and to prevent land and property grabbing, where adults attempt to rob orphans of their property once they have no parents to protect their rights.

United Nations Children's Fund (2007:4) states that "You find that the parents have been productive and have left assets for the children but immediately after their deaths, the relatives squander everything. Those that are left without anything are just being used for the food rations". Pelonomi Letshwiti, a social worker for Childline Botswana.

Children orphaned due to AIDS may face exploitation in other areas of their lives as well. For instance, evidence suggests that there is a relationship between AIDS orphans in Sub-Saharan Africa and increased child-labour (Children on the Brink, 2004:3).

In his opening address to the conference on orphans and other children made vulnerable by HIV and AIDS, the minister of Social Development, Dr Skweyiya, highlighted HIV and AIDS as the key challenge of our times (SARPN, 2007:1). The minister indicated that this key challenge tests our capacity to build truly caring communities. He further indicated that in South Africa in particular, the epidemic increases the population of orphans and vulnerable children, while reducing the pool of traditional caregivers and the number of breadwinners. The minister argued that South Africa's greatest challenge was identification of these children so that we have an idea of numbers, in order to plan accordingly. Dr Skweyiya mentioned that Census 2001 put

the numbers of child-headed households then at more than 248 000, while more than 30 000 children obtained the foster care grants. However, he maintained that there were many others that the department has not yet managed to reach. He indicated that it was in this regard that the provincial social departments are prioritising efforts aimed at bringing vulnerable children into the social safety net, in cooperation with the Department of Justice and Home Affairs.

The lack of social services support might lead to deprivation of caregivers from obtaining foster care grants for their orphans. This may in turn have the consequences of orphans escaping the social safety net, thus increasing their vulnerability. These vulnerable children could be forced into the streets, or suffer exploitation in the child labour force. Furthermore, this lack of social services support could contribute to further increase in population of vulnerable children, thus derailing the Social Development Department's efforts to obtain the exact number of these orphans and vulnerable children. It could also lead to the reduction in the pool of caregivers willing to give care to these orphans and vulnerable children. The minister of Social Development reiterated that what makes it imperative for the State and the nongovernmental sector to intervene was the pressure on community structures. These structures include the extended family system, which has traditionally acted as a safety net for children and orphans.

In 2004, the SASSA Act, 2004 (84/1996) was signed into law. With a view to operationalising Sassa, government has committed itself to ensuring that ordinary South Africans notice tangible changes to the social-assistance administration system, particularly as improved service delivery will affect them directly (Social Development Bulletin, 2007:4).

2.6.5 Meeting emotional needs of AIDS orphans

The physical needs of orphans, such as nutrition and health care, can often appear to be the most urgent (Olsen, 2005:9). But the emotional needs of children who have lost a parent should not be forgotten. Having a parent become sick and die is clearly a major trauma for any child, and may affect them for the rest of their life.

The Minister of Social Development, in the same conference on orphans and other children made vulnerable by HIV and AIDS, urged delegates to discuss one of the most critical but difficult issues, which was succession planning (SARPN, 2007:1). The Minister indicated that experience has deemed it necessary that in mitigating the impact of the epidemic on children, people need to proactively look at the issue of succession planning. He argued that families needed to confront this issue, and be assisted with the drawing up of wills and other important documentations and planning. The Minister asserts that such action will provide them with opportunity of choosing who will take care of their children, and what will happen to family assets such as the family home. Failure of parents in drawing up a will has led to fierce fighting between the paternal and maternal relatives of one of the orphans whose caregiver was interviewed in this study. The fighting was over the legal adoption of the orphans.

In fact, Levine reports that when a parent dies of AIDS in USA, surviving children face an uncertain future about their custody arrangements and financial benefits (Levine, 1995 as quoted by Ntozi, 1997). This kind of situation is also common in sub-Saharan Africa including South Africa. However, in most African countries paternal grandparents usually decide who should take care of the orphan. In a survey conducted in some regions in Uganda, households were probed on the person who made the decision on who is to care for the orphans. The study showed that the clan members (29.8%) followed closely by the parents (26.8%) and the orphans themselves (25.4%) made decisions (Ntonzi, 1997:29). The study showed that grandparents also made 14.8% of the decision-making. When such decisions are taken when parents are still alive, it may help in avoiding family members fighting over who is eligible to care for such orphans. This may also help improve the relationship between caregivers and other relatives.

2.7 CONCLUSION

This chapter presented a literature review on HIV/AIDS, AIDS orphans and caregivers. It highlighted the global, regional and local (South African) situation of HIV/AIDS. The chapter also shared some light on the impact of HIV/AIDS on children, as well as caregivers. This involved issues relating to people who provide care to AIDS orphans such as the nature of care needed for AIDS orphans. The next chapter presents the design of the empirical research.

CHAPTER THREE

EMPIRICAL DESIGN

3.1 INTRODUCTION

This chapter deals with the ways in which the empirical research of this study was designed. A qualitative research approach is employed to identify psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS. The rationale for the selection of the qualitative method of research is explained. Technical details such as the reliability and validity of the research method used in this study are also considered in this chapter.

3.2 QUALITATIVE RESEARCH METHOD

The qualitative research method was chosen as most relevant and suitable for identifying psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS, which is the aim of this study in Vanderbijlpark and Vereeniging. According to Strauss **and** Corbin (1998:72), Leedy **and** Ormrod (2001:149) and Brown **and** Jones (2001:13), one of the features of qualitative research is that it is interpretative in character, that is the inquiries try to account for what researchers have given an account of (by asking themselves questions, for example, why should learners orphaned as a result of AIDS be given care) and thereafter collect the responses from caregivers.

This interpretative character of qualitative research described above, is in line with the survey method considered for this research (Bodgdan **&** Biklen, 2003:147). Surveys are used to learn, among other things, about people's attitudes, beliefs, opinions and values (Charles, 1995:20). This corresponds with qualitative research in that qualitative research also enquires about attitudes, such as why people behave in the manner they do when in their natural settings (Denzin **&** Lincoln 1998:47; Brown **&** Jones, 2001:13).

Qualitative research also concentrates on verbal responses and approaches are not limited to formality. The scope is less defined, less structured and data appears as words (Bodgdan **&** Biklen, 2003:7). Strauss **and** Corbin (1998:91) argue that qualitative

research is a foundation aimed at covering various methods and approaches into the inquiry of human behaviour. It includes exploring the world of people interviewed, researching their background and examining the information gathered with the purpose of establishing the meaning of facts being provided. What people perceive tends to expose how they think things should be, whereas what is initially identified is more likely to reveal how things are, especially when field observation extends throughout an adequate period of time (Denzin & Lincoln, 1998:56). In the context of this research, the psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS were established.

McMillan and Schumacher (1997:390) contend that, by trying to understand and observe a problem, qualitative research may enhance the following elements of endeavour related to educational intervention in the identified patterns of human behaviour, namely:

- establishing which causal factors can be influenced and which cannot; and
- predicting transformation that might be introduced in the domains concerned.

In the light of the above paragraphs, the qualitative research method may be explained as a guideline which produces descriptive information as engaged in people's own written or verbal words and identified behaviour rather than in figures. This implies that the correct meaning of perception held by psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS should be deduced (Denzin & Lincoln, 1998:35). McMillan and Schumacher (1997:233) further assert that qualitative research interprets reality as interactive and as a distributed experience viewed by individuals. In this research, different psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS, are examined and a relevant conclusion is reached.

3.3 RATIONALE FOR CHOOSING THE QUALITATIVE RESEARCH METHOD

The qualitative research method was considered with the purpose of revealing the psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS. Due to the evidence that various people view the world

differently, responses of caregivers are sought in order for relevant conclusions to be drawn. The qualitative method of research is viewed as appropriate for this research because it becomes possible to measure the reactions of many people to a limited set of questions, thus facilitating direct comparisons between people (Best & Kahn, 2003:241).

The word qualitative signifies that emphasis is placed on processes and meanings, not accurately scrutinizing or measuring in terms of quantity, amount, magnitude or frequency. The socially assembled nature of reality is stressed; answers are sought about questions and subsequently given meaning (Leedy & Ormrod, 2001:147-148; Denzin & Lincoln, 1998:4). In this regard, qualitative inquiry gives rise to new questions, expands the frame of reference of the individual and enables the examination of evidence in a productive manner. Qualitative researchers also concentrate on natural settings as they are interested to discover new insights. Nothing is taken for granted and they want participants who are the focus of the study to speak for themselves (Henning, van Rensburg & Smit, 2004:1-5; Leedy & Ormrod, 2001:149; Best & Kahn, 2003:240). In present research, caregivers of learners orphaned as a result of AIDS are the focus of the study and they respond to particular questions. An open-ended section where the opinion of the participant is invited accompanies each question. This is necessary in present research because when caregivers speak for themselves, new insights are discoverable about their psychological, social and economic problems they experience when giving care to learners orphaned as a result of AIDS.

Qualitative research also places emphasis on comprehension by paying attention to the words used by people and the intention of such research is to discover patterns emerging from thoughtful analysis of the research topic. Socially contextualized findings and limited generalizations are the discoveries made through qualitative research (Evans, 1995:55; Bodgdan & Biklen, 2003:10).

Finally, qualitative investigation broadens the understanding of educational research by extending the researcher's frame of reference. It provides a means of counteracting rationalization of researchers and assists them to search for universal and infinite generalizations. In present research, the qualitative method of investigation should

provide constant truths pertaining to the concept of psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS (Leedy & Ormrod, 2001:147).

Strauss and Corbin (1998:30) indicate that the qualitative researchers should apply the following important concepts:

- qualitative research is designed to discover what can be learned about a phenomenon of interest;
- qualitative research has various interpretations. It reveals logistics and the relevance, which has an influence on the readers. It enables a researcher to gain insights about the nature of a particular phenomenon. It develops new concepts or theoretical perspectives about the phenomenon and also discovers the problems that exist within the phenomenon;
- impressive conceptions, related to the origin of truth of the world, the nature of certain situations, settings, processes, relationships, systems, or people, are revealed;
- the focus is based on the participants' ideas and experiences;
- simple social events in their original situations display aspects of real life in the research process;
- it assists in the justification of correct life skills and the future success of the individual;
- it stresses identification, induction and formulated theory;
- it involves the participant's observation in detailed interview and conversational analysis;
- it allows a researcher to test the validity of certain assumptions, claims, theories and generalizations within real world contexts; and
- it provides a means through which a researcher can judge the effectiveness of particular policies, practices and innovations (Best & Kahn, 2003; Charles, 1995:21).

From the foregoing paragraphs it is clear that qualitative research methods enable the researcher to investigate selected matters in depth and detail. The nature of the qualitative method used in this research was interviewing.

3.3.1 Interviews

The interview was selected as an instrument to be used for collecting information as well as to give clarity on certain questions posed in the interview schedule. Through the interviewees, the researcher has the chance to discuss, answer and pose questions related to the phenomenon (Rubin & Rubin, 1995:36). This method is regarded as characterized by open-response questions which enable the researcher to determine in what way participants interpret their world and how they interpret events in their lives. This type of interview provides researchers with a uniform method of recording information, and therefore enhances the validity of the interview as a measuring instrument (Evans 1995:53; Bodgdan & Biklen, 2003:121).

Conducting an informative interview is not as easy as it might seem. Eisner (1998:183-185), Best and Kahn (2003:255-257), Henning, van Rensburg and Smit (2004:50-56) and Briggs (2002:916) offer the following guidelines to researchers for conducting productive interviews:

- **Make sure interviewees are representative of the group** - The researcher should choose people who are expected to give typical perceptions and perspectives. In some cases, the researcher may intentionally “pick extremists” who should be identified as such in the notes.
- **Find a suitable location** - In theory, the researcher can conduct an interview anywhere people are willing to talk. It will probably be a more successful interview if a quiet place is found where the interviewee is unlikely to be distracted or interrupted.
- **Take a few minutes to establish rapport** - Commence the conversation with small talk that can break the ice. Be courteous and respectful at all times.
- **Get written permission from participants** - Explain the nature of the research and plans for using the results. Ask the participants to sign an informed consent

form. Offer to provide an abstract or copy of the research report once the research is completed.

- **Focus on the actual rather than on the abstract or hypothetical** - Researchers are more likely to get revealing information if they ask what a person does or would do in a specific situation.
- **Do not put words in participants mouths** - Let participants choose their own way of expressing their thoughts. A good interviewer is a good listener who lets people say what they want to say in the way that they want to say it.
- **Record responses *verbatim*** - Whether researcher uses handwritten notes, shorthand, or a tape recorder, everything the participants says should be captured, especially if the interview is an unstructured one. If the researcher suspects that an interviewee may have said something other than was intended the response must be played back to check accuracy.
- **Keep your reactions to yourself** - Although researchers would not necessarily want to maintain a continual “poker face”, they are more likely to get accurate information if they do not show surprise or disapproval of what is being said.
- **Remember that researchers are not necessarily getting the facts** - As confident and convincing as some participants may be the researcher should always treat their responses as perceptions rather than as facts.

In qualitative research studies, interviews are often quite open-ended, revolving around one or two central issues while addressing different social problems for different participants (Laws, Harper & Marcus, 2003:197; Kitchin & Tate, 2000:12). In survey research, interviews are more structured. In a structured interview, the researcher asks a standard set of questions and nothing more. In a semi-structured interview, the research may follow the standard questions with one or two individually modified questions to get clarification or probe a person’s reasoning (Gubrium & Holstein, 2002:13). In this research the researcher used personal interviews.

Personal interviews have the distinct advantage of enabling the researcher to establish rapport with potential participants and therefore gain their co-operation (Henning, van Rensburg & Smit, 2004:66-67). It also allows the researcher to clarify ambiguous

answers and when appropriate, seek follow-up information. These interviews take time and may not be effective when very large sample sizes are incorporated in the particular research (Johnson, 2002:103).

The following are advantages of interviews:

- by making personal contact, interviewees get the impression that they are being valued and they therefore provide sincere responses;
- the interview setting enables the interviewer to clarify questions that participants may find confusing;
- participants may broaden their answers or be limited from the central topic in ways that prove useful to the researcher; and
- provide an in-depth understanding of participants' motives, their pattern of reasoning and emotional reactions not possible with questionnaires (Thomas, 1998:135).

The main disadvantage of interviews is that they are more expensive and time-consuming than questionnaires (Frey & Oishi, 1995:3).

An interview was planned for identifying the psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS. Rubin and Rubin (1995:56) claim that an interview permits the interviewer to maintain an understanding of what the interviewee means by responses he/she gives to questions asked. Interviews have been employed extensively across all the disciplines of the social sciences and in educational research as a key technique of data collection.

The following features (Thomas, 1998:134) are deduced from interviews:

- interviewers can probe for more specific answers and can repeat a question when the response indicates that the interviewee has misunderstood the question;
- an interview does not have a time limit, people who cannot read and write could still answer questions in an interview;
- the interviewer is present to observe non-verbal behaviour as well as to assess the validity of the interviewee's answers;

- the interviewer may standardize the interview environment, for example by making sure that there is privacy and no noise;
- the interviewer has full control over the order of questions to be answered;
- the interviewee cannot retract an answer once it has been given and thus the interviewer can record answers from the interviewee as they arise;
- the interviewer can ensure that all questions are answered;
- provide an in-depth understanding of the participants' motives, pattern of reasoning and emotional reactions not possible with questionnaires; and
- the interviewer can record the exact time, data and place of the interview (Thomas, 1998:135).

In this research, the participants were requested to be interviewed and informed how important this research could be in adding to existing information on the caregiving of AIDS orphans. They were also told before the interview that the research may also provide solutions or alternatives to problems AIDS orphans faced and thereby contribute to the improvement of their psycho-social well-being and wellness.

A semi-structured interview was employed in this study, during which the researcher listened intently, made notes and where necessary, sought clarity or more information from interviewees (Laws, Harper & Marcus, 2003:198; Kitchin & Tate, 2000:212).

The interviews were conducted as follows:

- the interviewer introduced herself and explained the need for the interview and how the interviewees were selected;
- secondly, questions were asked and answers were recorded. The interviewer accurately recorded answers and did not summarize or paraphrase, because this may have caused loss of information or could have distorted the answers;
- thirdly, the interviewer elicited to seek clarity from the interviewees by means of asking probing questions to supply more information. A probe is a neutral request to clarify any ambiguous answers or to obtain a relevant response; and

- finally, the interviewer thanked participants and then entered details like time, place of interview and attitude of participants. Every disturbance that might have taken place, such as a phone ringing and the participants going to answer it for ten minutes was also recorded (Neuman, 1997:258).

In order to reach the correct conclusion for this research, it is necessary in the next section to focus on the character of a research instrument.

3.4 CHARACTERISTICS OF A RESEARCH INSTRUMENT

An imperative attribute of research instruments is the existence of reliability and validity, the latter being the most important characteristic (Bryman & Cramer, 1999:5; Thomas, 1998; 133). Mouton (1996:78) postulates that research is a scientific method of enquiry, thus information should be carefully assessed by means of reliability and validity focuses on the trustworthiness (Charles, 1995:101), which invite explanation of phenomena reliability and validity. Validity involves what is intended to be evaluated and for whom it is relevant, whereas reliability includes the consistency with which the instrument appraising whatever should be measured (Thomas, 1998:138; David, Bryd & McIntyre, 1999:49).

3.4.1 Validity

The relevancy, meaningfulness and usefulness of conclusions made by researchers, can be defined as the validity thereof (Henning, van Rensburg & Smit, 2004:146-149). Strauss and Corbin (1998:76) state that validity is employed to guarantee that information includes everything it should and that it does not include anything that should not be included. Validity is the way of discovering a true and precise picture of what is claimed to be described and is dependent on the purpose in which measurement takes place (Rubin & Rubin, 1995:85; Charles, 1995:102; Laws, Harper & Marcus, 2003:417; Kitchin & Tate, 2000:35). The results of an interview can therefore be valid in one situation and invalid in another.

Validity, therefore, is the degree to which a survey instrument evaluates what it purports to measure (Best & Kahn, 2003:166). For instance, the research of the psychological,

social and economic problems experienced by caregivers of learners orphaned as a result of AIDS, is valid if the researcher formulates and asks questions that are relevant to psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS.

A more appropriate definition of the concept validity is provided by Best **and** Kahn (2003:166) below.

"Validity is concerned with the accuracy of scientific findings. Establishing validity requires: determining the extent to which conclusions effectively represent empirical reality, and assessing whether constructs devised by researchers represent or measure the strategies of human experience that occur".

The functionality of present research is to ascertain the concepts pertaining to psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS. Reality is represented in the interview schedule (cf. Appendix 1) used in this research by posing questions which are relevant to the concepts of the psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS, and supported by the fact that it is relevant to human experience as well. Therefore only caregivers taking care to AIDS orphans were requested to participate in this research. Accurate interpretation of results can only be made if the group to be studied precisely conforms to specified standards in all aspects.

To obtain validity, Leedy **and** Ormrod (2001:31) and Fink (1995:500) claim that the researcher has to employ standards which may have a meaningful link with research questions and with data analysis, in order to direct him/her in creating valid arguments, findings and reports. This emphasis is considered with the idea that validity is a single unitary concept that requires evidence for the specific use that it cited. The questions posed in the interview schedule are of such a nature that ambiguity should not occur in response. Reliability, dealing with the consistency with which an instrument evaluates, is closely linked to the concept of validity.

3.4.2 Reliability

Reliability refers to the consistency of measurement to the extent with which the results are similar over different forms of the same instrument or occasions of data collecting (Leedy & Ormrod, 2001:31-32; Best & Kahn, 2003:276-277). In other words, the same results are obtained each time the researcher uses various techniques for assessing the collected data (Charles, 1995:103). Charles adds that reliability, in ordinary terms, means dependability or credibility. With respect to measurement, the meaning is similar. The ratio to which a test constantly measures what it is intended to measure, is referred to as the reliability thereof. If a reliable test were to be re-administered, the scores obtained would essentially reveal similar scores the second time.

Reliability directly points to the consistency of the scores acquired. If scores are inconsistent they provide no useful information and cannot be declared valid. If reliability of a test improves, the validity improves as well (Henning, van Rensburg & Smit, 2004:146).

The questions contained in the interview schedule are aimed at concepts relevant to the psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS which safeguards that only relevant responses will be given. There might be errors in a set of collected data; therefore reliability is utilized with the aim of achieving a more precise reflection of the truth. Clear and relevant questions were formulated for the interview with the purpose of attaining reliable data that is free from measurement mistakes (Mouton, 1996:97).

The next section gives a careful thought to sample selection and data collection.

3.5 POPULATION AND SAMPLE SELECTION

Cormack (2000:51), Best and Kahn (2003:12) and Leedy and Ormrod (2001:223-224) postulate that sampling is a process of choosing a small group of participants from a defined population. They further define sampling as the scientific research in which a number of individuals are stakeholders in establishing a concise conclusion about a large number of people. Sample selection is the primary technique used to collect data and the manner in which cases rich in information, present themselves.

The reasoning behind sampling is associated with the purpose of the research as well as the research problem studied (Evans, 1995:56; Best & Kahn, 2003:12). Cormack (2000:52) states that, when an educational design is in the planning stage, the researcher should take the population, to which the results should be generalized, into account. Such intention should involve decisions over sample sizes and sampling methods. Qualitative research is mainly focused on the description of the site and sample (Frey & Oishi, 1995:14-15). In this instance, questions regarding where, how and with whom a particular phenomenon prevails, may be asked. Best and Kahn (2003:342) and Frey and Oishi (1995:16) emphasize the importance of a selection strategy which should be employed in order to achieve the sub-set of the population from whom data is collected by means of interviewing, observation and documentation. It is therefore important to conceptualize sampling as an aspect of research.

This research has chosen a specific population, which comprises the population of caregivers of AIDS orphans in the Vanderbijlpark and Vereeniging districts, in the Vaal Triangle. Due to a large population of caregivers taking care of AIDS orphans in these districts, the population sample was limited to the following categories of families:

- two caregivers in Vereeniging who were personally known by the researcher to be taking care of AIDS orphans attending at her school
- five caregivers provided by Bophelong primary schools in Vanderbijlpark.
- four caregivers provided by social workers (Three from Bophelong in Vanderbijlpark and one from Sharpville in Vereeniging) – n=11.

The sets of caregivers interviewed ranged from single- to two-parent families. Furthermore, the families were categorised as foster-home, extended and child-headed family. In certain selected cases relating to specific caregivers, people from the following organisations were interviewed in order to get more clarity on the facts provided by the caregivers:

- nine members from a non-governmental organisation (NGO) working on different HIV/AIDS related cases and community related projects – n=9;
- seven school teachers of one of the affected orphan – n=7; and

- two family members of one of the orphans – n=2.

These follow-up interviews were conducted with the consent of the caregiver, and were necessitated by a need to verify some of the information given by this caregiver, as well as comparing the responses with the literature.

3.6 EMPIRICAL RESEARCH DATA COLLECTION

Empirical research data collection forms an important part of any research because it does not only give a description of what empirical research data could be collected and how it should be collected but it also constitutes the basic primary information from which conclusions are drawn (Coleman, 1998:161; Bryman & Cramer, 1999:5). It creates an essential component of any research because it does not only supply an explanation of what data is collected and how it is received, it further impacts the important data from which conclusions are drawn (Best & Kahn, 2003:254; Bassey, 1999:81).

The instrument that was used to collect data in this research was an interview schedule. The interview schedule was the research measuring instrument used in order to collect primary information. The researcher made use of interviews to formulate an opinion about the psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS. In order to follow this course, the researcher had to obtain permission from all the above stated participants to voluntarily participate in the study.

3.7 THE INTERVIEW SCHEDULE

Different interview schedules (see Appendix Schedules 1, 2, 3 & 4) were used to conduct research, in order to select a sample of participants and administer an interview schedule to collect empirical research data. The items in the interview schedules were developed by the researcher according to the method suggested by Reason and Bradbury (2001:329), Mouton (1996:36) and Bounds, Malgee and Mayhew, (2005:37).

The interview schedule is the most broadly used technique for acquiring qualitative research information from participants. It is relatively economical, contains structured or unstructured questions, ensures that the participants remain anonymous and the questions can be asked with a specific purpose in mind (Evans, 1995:55; Best & Kahn, 2003:301).

Interview schedules are conversationally administered to resolve opinions, attitudes, preferences and perceptions whereas studies that deal with sensitive topics that invoke a deeper response that cannot be measured by means of a questionnaire. Complex responses are not required where the concept or notion of the psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS. This qualitative research dissertation therefore revolves around opinions, attitudes, preferences and perceptions on the psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS. The above mentioned method of obtaining information about the psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS is regarded appropriate for the present research. Certain practical considerations require attention to ensure the functionality of the interview schedule.

3.8 DEVELOPMENT OF THE QUESTIONS FOR THE INTERVIEW SCHEDULES

Piantanida and Garman (1999:250), Bassey (1999:67) and Best and Kahn (2003:303-308) indicated that once objectives have been defined and it has been ascertained that no existing methods can be used, the task of writing the questions may begin. It is best to write the items objectively and to consider the way the results are analyzed once the data has been collected (Reason & Bradbury, 2001:83). In this research all questions that were deemed irrelevant were eliminated. It is essential to provide clarity to what the researcher wants to achieve by posing the types of questions listed below. Questions listed below solicited the opinion of participants on issues related to the psychological, social and economic problems experienced by caregivers of learners orphaned as a result of AIDS.

Generally, the questions were designed to investigate the impact of HIV/AIDS on caregivers, with regard to the following factors:

- Family background;
- Emotional and health;
- Financial;
- Social

Although not structurally arranged during the interview, typical questions, which guided the interview, are contained in different appendices (see Appendix Schedule 1, Appendix Schedule 2, Appendix Schedule 3 and Appendix Schedule 4).

Questions 1 to 6 (see Appendix Schedule 1) sought to investigate the family background of caregivers. This background is necessary because it has some effects on the aspects being investigated, that is, the emotional; economical; social and health impact of HIV/AIDS on caregivers. Questions 7 to 16 (see Appendix Schedule 1) investigate the general emotional impact of HIV/AIDS on caregivers, while questions 17 to 19 (see Appendix Schedule 1) investigated the health impact. Questions 20 to 27 (see Appendix Schedule 1) investigate the extent to which caregivers are subjected to the financial impact of HIV/AIDS. The impact of HIV/AIDS on the social life of caregivers is investigated in questions 28 to 36 (see Appendix Schedule 1).

Questions 37 to 43 (see Appendix Schedule 2) sought to verify from grandparents of caregiver one's orphans, while Questions 44 to 56 (see Appendix Schedule 3) sought to get clarity from educators of the same orphan. Questions 57 to 64 (see Appendix Schedule 4) sought to establish any community help given to orphans and their caregivers.

3.9 ETHICS AND INFORMED CONSENT

Since the nature of the empirical research that was conducted for this study is highly invasive of intimate aspects of the participants' lives and their lived experiences, great care was taken to protect research participants by obtaining permission from legal guardians where health authorities or schools were contacted. A copy of this letter of permission is contained in Appendix 5.

3.10 CONCLUSION

In this chapter the empirical research methods of data collection were described in detail. Clarity was provided for reasons of using qualitative methods of research. Characteristics of a research instrument, population and sample selection also received attention. A research instrument, namely an interview schedule was explained. The reasons for including specific questions in the interview schedules were also given attention. Questions asked in the interview schedule were also clarified.

The next chapter deals with the analyses and interpretations of the empirical research data which were collected during the interviewing sessions.

CHAPTER FOUR

ANALYSES AND INTERPRETATIONS OF THE EMPIRICAL RESEARCH DATA

4.1 INTRODUCTION

Chapter four provides analyses and interpretations of the empirical research data, which the researcher elicited, from the participants. Bodgdan and Biklen (2003:147) postulate that analysis is a way of gathering and explaining the content of text. The content includes meanings, thoughts, words, themes and messages that can be communicated. The text in this regard is anything written, visual and spoken, which is utilized as a medium for communication.

Collected data has to be analysed and organized before interpretations can be made (Charles, 1995:35). Firstly, data analysis is defined and thereafter responses from caregivers of AIDS orphans are presented.

Data analysis is the way of choosing, classifying, viewing and discarding information. In this research, the mass of collected empirical research data were analysed and interpreted with the purpose of bringing order and structure to information (Bassey, 1999:81). The researcher assumes that caregivers of AIDS orphans experience emotional, economic, social and health problems.

Analyses of empirical research data in qualitative research involve logic. This implies that reasoning is used and conclusions are drawn based on evidence (Strauss & Corbin, 1998:58). Bassey (1999:83) stipulates that once reasoning draws a conclusion, it should clarify the logic of the data for analysis purposes. In this process of research, the researcher investigates patterns of similarities and differences and attempts to disclose their diversity. The researcher is responsible and accountable to establish the extent to which materials are valid and reliable (Strauss & Corbin, 1998:179). Charles (1995:48) further emphasizes that reliability and validity of the participants' responses should be maintained as far as possible.

4.2 RESPONSES OF CAREGIVERS (N=11) WHO FORMED THE POPULATION SAMPLE OF THIS RESEARCH

This section provides the responses of the eleven caregivers (n=11) who formed the sample population of the empirical research of this study.

4.2.1 Questions one to six of the interview schedule sought to investigate the family background of caregivers

The family background of caregivers who participated in this research was necessary because the researcher assumes that the plight of AIDS orphans could have an impact on the emotional, economical, and social and health impact of their caregivers.

All caregiver participants responded to questions one to six (see Appendix 1) such as:

- How many orphans are under their care?
- How did they know about the orphans, and why did they take them into their care?
- What is the relationship between them and the orphan/s?
- For how long have they provided care giving?
- What type of parenting are they giving to this/these orphan/s (for example, adoption or foster)?
- Could they explain the type of family structure that exists in their home (for example, single; traditional; child-headed or orphanage)?

It is also worth noting that these questions were not asked in any particular order, but were dictated by the responses received from the participants. The following responses were received and are presented *verbatim*:

4.2.1.1 Caregiver one's responses to questions one to six

"We are a traditional type of a family, where me and my husband give care to two orphans, a brother and his younger sister. We have now legally adopted the two orphans after your (refers to, me, the researcher's) intervention". This caregiver was identified after the researcher was requested by one of the boy orphan's educator to investigate circumstances leading to his poor health and educational conditions. The researcher is a member of a School-Based Support Team, which is responsible for

giving support to learners affected and infected by HIV/AIDS and learners orphaned by HIV/AIDS. The school-based support team is also responsible for learner support and guidance, working with police, social workers, community health centres and district education departments to form an ecosystemic network with them for the psycho-social and physical development of these learners. In the process of helping the two orphans, which is part of her lived advocacy way of life as a social constructivist, the researcher organised appointments with social workers for the lady caregiver, so as to initiate the adoption process. Although the caregivers were now caring for the orphans, they did not have control over the foster care or child grants of these two orphans. The orphans' grandparents were responsible for the collection of the social grants from the Department of Social Development and Welfare.

"I'm the aunt to the two orphans since their mother was my sister. However, these two orphans were initially living with their grandparents from my mother's side, after the death of their mother in 2003. Their father disappeared just before the death of their mother. I discovered during my visits to my parents that the two siblings were not receiving proper childhood care from their grandparents. However, it was only after I was requested by one of the educators of the boy orphans, to come and discuss his worrying conditions at school that I decided to take them under my care".

4.2.1.2 Caregiver two's responses to questions one to six

"We are a normal two-parent family giving care to two orphans, who are a boy and a girl. The two orphans are my grandchildren from my two daughters. I have been taking care of these children since the death of both their mothers a year ago. Although one of the orphans' fathers is still alive and they are aware of his whereabouts, their mother's death wish was that her children should be under our (grand-parents') care and not their stepmother's. Their mother was worried that their father might get married to another woman after her death and the chances that his new wife would take good care of her children were slim".

4.2.1.3 Caregiver three's responses to questions one to six

"I give care to two orphans who are a brother and sister. The two siblings are related to

my partner. We have been living together for few years but are not legally married. He is a brother to the two orphans. We have tried to adopt the orphans but our attempts were frustrated by the fact that we are not legally married. Although the social workers have advised us to just sign at the commissioner's place, I'm reluctant because I would not get the approval of my parents without the cultural obligations my future husband has to satisfy".

I informed the caregiver that as far as I can remember, there is no law prohibiting the couple to legally adopting the orphans. However, I promised her that will do some research regarding adoption of orphans in South Africa, and advise her appropriately.

"The two siblings do not share the same father. We were already living with the boy orphan while his mother and stepfather were still alive. Initially, this boy used to live with his grandfather, but then decided to live with us after some time. At that stage, his sister was living with her parents. However, when her mother's illness got worse, her father sent both of them to her (orphan) grandfather to take care of them, as his health was also not good. The orphans' parents died one after another. We only took care of the girl orphan after we were approached by one of her educators. The educator informed us that she was worried that the two siblings do not seem to be getting the same care. After we explained the situation of the two orphans to the educator, and that they were unable to take her into their care due to family politics, the educator pleaded with us to reconsider our decision".

4.2.1.4 Caregiver four's responses to questions one to six

"I am a single parent giving care to four orphans and one vulnerable child. I'm legal foster parent. I was initially giving care to five orphans. However, one of the orphans ran away from my care. While this run-away was still away, she gave birth to a child, whom she gave up for adoption by me. The ages of orphans in my care range from 11 months to sixteen (16) years. The 11 months old baby is actually the daughter of this orphan who ran away from my care".

The caregiver explained during the interview that this run-away mother gave her child up for adoption since she did not want her child to be aware of the type of life she was

living. It was apparent from the discussions that the caregiver was aware that this run-away orphan might be involved in prostitution, even though she did not say it. When asked whether she has informed the social workers about the life that this run-away orphan is leading, she said that it was difficult for social workers to trace her.

"I have legally secured fostering of these orphans with the Social Development Services Department in Johannesburg. You see, I was initially living with my foster children in Soweto before relocating to Vanderbijlpark. My desire to adopt orphans is inherent in my family, and it's like a family legacy. My own parents had adopted children from various backgrounds. Both the orphans and myself do not know the other orphans' family backgrounds".

4.2.1.5 Caregiver five's responses to questions one to six

"I am a single parent giving care to two twin brothers who are eight years old. I'm a sister to this other caregiver. I like my sister here, applied with the Johannesburg social services department for fostering orphans. The twin brothers were born to a woman who originated from one of the coloured township in the Cape. Their mother came to Johannesburg to work in one of the sex industries in Hillbrow. I adopted these orphans while their mother was still alive. However, their mother has since died from HIV/AIDS related illness".

This caregiver is a sister to caregiver NK, and they were interviewed at the same time as. She is the one who was requested to care for her sister's orphans when she was away to their mother's place.

4.2.1.6 Caregiver six's responses to questions one to six

"We were a stable two-parent family giving care to our grandchildren. However, their grandfather has since passed away. I am giving care to three orphans, one of which is a twin. This twin is living with her other two sisters. Her twin brother lives with her aunt because of fierce fighting between them (twins). They were fighting everywhere that is at home, school and even when they were playing with the other children. Their mother died from HIV/AIDS related illness. The twins and their sisters have three different

fathers who are all not known to me. I'm living in this shack, which does not even have windows".

I was quite perturbed by the conditions in which the family was living, and promised that I would try to see if I could pull some strings to help find them a better place such as an RDP house. Although I knew it could be very difficult to do that, but my belief was that with my influence as a researcher, I might be able to succeed.

4.2.1.7 Caregiver seven's responses to questions one to six

"We are a two-parent family giving care to two brothers. I'm the aunt to the two orphans, and have legally adopted them. We started giving care to these orphans when their mother was critically ill. Their father had also died. They were orphaned due to HIV/AIDS. We were forced to take care of these orphans because none of my other fourteen siblings would have anything to do with the two orphans".

4.2.1.8 Caregiver eight's responses to questions one to six

"I am taking care of six orphans, and I'm a single parent. I have legally adopted all the orphans. Some of these orphans were adopted from the social services departments through the help of social workers; while others were picked up from the neighbourhood after their parents had died from HIV/AIDS related illnesses. Their relatives rejected most of these orphans because their parents had die of HIV/AIDS. In fact, one of the orphans used to live with his grandfather. This orphan was related to me and I had once taken care of him even when his parents were still alive. Her parents asked me to take the child to the doctor when he was ill. However, his parents took him back when he was cured from his illness. After the death of his parents he was taken to live with his grandfather. However, I discovered during the funeral of the orphan's grandfather that he was not having any communication with his grandfather. He spent most of his entire life looking after his grandfather's cattle. When he came back home in the afternoon, he would eat and then go to his bedroom. This affected his speech".

"Another of my orphans, who is a girl, was living with her grand-mother and her uncles. The child used to visit the caregiver during the day and she would force the child to go

back to her family at night. However, I noticed that the child would be reluctant to leave and cry hysterically”.

“One day I decided to visit the child’s place to investigate why the child was not happy to go back to her place. After I had knocked at the door several times without any answer, I opened the door. I was shocked upon entering the house to find the child sleeping between her uncles. When I asked if there was any woman in the family, I was told that the child’s grand-mother was a busy woman and does not spend most of her time at home. I then requested the uncles if I could take care of the child until her grand-mother can make herself available for the child. Ultimately when the grand-mother arrived at home, the child’s uncles informed me that one of the neighbours had taken her to my home. She then came to me to enquire about the child. I then informed her about the situation at her home, and even requested the grand-mother to allow me to care for the child. The grand-mother said she would be pleased, and in fact she would be relieved, as she is unable to take good care of the child. The grand-mother even went together with me to the social workers to arrange for formal adoption”.

4.2.1.9 Caregiver nine’s responses to questions one to six

“I’m single and giving care to my younger sister who is seventeen years old. We are orphans and my mother died from HIV/AIDS related illness in 2004. We have been living together since the death of my mother”.

“I have a boyfriend, however, he does not live with us. He comes to visit frequently and he is working. I am presently a first year student at Vaal University of Technology. I am doing a degree in analytical chemistry”.

4.2.1.10 Caregiver ten’s responses to questions one to six

“We a traditional two-parent type of a family. I’m looking after my brother’s two children. Their parents died within three months of each other’s death. Although my brother was very secretive about his personal life, the manner in which both him and his wife died, gives one the impression that their deaths must have been HIV/AIDS related. You see, it’s our belief that it’s our obligation to take care of my brother’s children, as tradition

necessitates. However, the adoption has not yet been finalised as their mother had given her children to the care of her younger sister just before she died. This has created a bitter war between the two families. The older orphan is sixteen years old, while his sister is seven years old. The two orphans are currently staying with their uncle, from their mother's side because they are closer to their schools".

It was apparent during the interview that the two families, which are from the orphans' mother and father sides, were fighting over the adoption of the orphans. The caregivers indicated that the other family's lawyer informed them that the orphans' mother has given them under the care of her younger sister. However, there was no testament indicating this. It was also clear that the orphans' parents were not having good relationship with each other before their deaths.

I mentioned to the caregiver that usually the mother would always try to ensure that when she dies her children are given to the care of someone that she trusts. So, it was possible that she has given her children under the care of his sister because she was convinced that she is the best person to do that. However, I can also understand their reasons for wanting to care for the two orphans, as tradition dictates. I advised them to seek advices from the social workers, as they are the best professional people to address the problem. I informed them that they should also be prepared for any shock since social workers always resolve adoption problems for the benefit of the child only, not the feuding parties.

4.2.1.11 Caregiver eleven's responses to questions one to six

"I'm a single-parent family. I am 22 years old and I'm caring for my younger brother. I started caring for my younger brother after the death of our mother about 5 years ago. After the death of our mother, we were taken cared of by our grandmother, who is now ninety-seven years old. Our father was not staying with us as he was working away from home. After the death of our mother, our father only sent us money. However, our father also died and I was forced to quit school since our grandparents could not afford to pay our school fees and support us with other things. I was then forced into marriage so as to support my brother and my grandparents. However, the marriage did not last long, as I suffered emotional, physical and sexual abuses from my husband. I am

currently working as a domestic worker, and only see my family once a month. My brother and my two children still live with my grandmother, whose health conditions are deteriorating at a very fast pace”.

4.2.2 Questions seven to sixteen investigated the general emotional impact of caring for AIDS orphans on caregivers

The caregiver participants responded to the following questions:

- How is the relationship between them and the two AIDS orphans?
- Do they have any other children except the two AIDS orphans?
- How is the relationship between their children (if any) and the two AIDS orphans?
- How is the relationship between their relatives and the two AIDS orphans?
- Are any of the two AIDS orphans infected with HIV?
- Are the two AIDS orphans aware of their HIV/AIDS status?
- How does carrying for children orphaned due to HIV/AIDS affect their approach to life?
- Do they personally give treatment to orphans infected by HIV?
- Have they received any training or counselling regarding treatment of HIV infected persons?
- Would they advise other people to be caregivers?

The following is a *verbatim* account of the general emotional impact of caring for AIDS orphans on caregivers, as highlighted by the responses of the caregiver participants who formed the sample population of this study:

4.2.2.1 Caregiver one's responses questions seven to sixteen

“Every time I look at these two orphans, it reminds me of my late sister, who is the mother of these orphans. My relationship with both two orphans is very good, and besides, I consider them as my own children. We have three other children of our own, and they are currently having good relationship with the two orphans, and regard them as their own brother and sister. However, I am worried that the boy orphan's arrogant attitude may lead to my own children developing an intolerable attitude towards him”. The caregiver has another sister who sometimes has to take care of the orphans when a need arises.

"I must emphasise that the two orphans' relationship with their other aunt is good as she also helps in giving care to the orphans. Although I have a good relationship with my sister, my relationship with my father, who is the two orphans' grandfather, is not that healthy. This has even led to my sister's relationship with our father being severed. The severity in the relationship is because of my parents' insistence that they should control the social grants that the orphans are receiving". As mentioned earlier, the grandparents controlled the social grants until it was transferred to the caregiver, after legally adopting the two orphans through this researcher's intervention.

"The boy orphan is also HIV positive and is currently under medication. Although he was diagnosed with HIV, he is not aware of his status because I want to protect him. I only tell him that he is suffering from tuberculosis. Furthermore, even though I am married, I do not even inform my husband about the boy's health conditions". I first discovered that the boy orphans' health was very poor during my interaction with the educator who brought the situation to my attention. However, the caregiver had another problem with the other orphan. Although this orphan had not been diagnosed as HIV positive or having AIDS, she had some other disabilities that the caregiver highlighted during the interview. "The boy's sister has speech problems, as well as passing urine uncontrollably. This problem started from her birth until she was given help, after your (researcher's) intervention. After having been given some medication, her speech started improving and she could go to the toilet on her own and pass urine, as the demand arose". It was very clear that due to the severity of the girl orphan's medical conditions, the situation needed some urgent advocacy from this researcher. This researcher immediately arranged for her to see a psychiatrist at Johan Heyns clinic in Vanderbijlpark, where she was diagnosed as having high depression as well as suffering from slow milestone.

The boy orphan's behaviour was worrisome to the caregiver, and it was quite apparent that this was having an emotional effect on her. "When the boy orphan is given punishment for his misbehaviour, he would cry and call his mother's name. This creates an emotional conflict within me, as I am not sure if I am doing the right thing by giving this child some punishment. Sometimes, he would hide the money that I give to him, and then request money from his educators and fellow learners. This creates problems for me, as I would often be called to the school to account for his bad behaviour.

Sometimes, I would even be accused of not giving necessary support to the child. However, although I feel that the arrogance of the boy orphan sometimes makes it difficult for me to emotionally cope, I want to maintain that I am quite happy to be caring for these two orphans. I would even encourage other people to give care to orphans”.

4.2.2.2 Caregiver two's responses questions seven to sixteen

“My relationship with these two children is that of a normal type of a family where I still consider them as my grand-children, not because their mothers have died. My worry is that these children seem to be struggling with their academic and scholastic work. This is not giving me peace because I thought may be the problem was with me since I could not help and support them with their academic and scholastic work. When I went to their school to enquire about their academic and scholastic performances, I was assured that their poor academic and scholastic performance could be related to the trauma of their loss of their mother”.

The loss of the loved ones affects different people differently. Some are able to deal with their loss much faster, while others take some time to recover from their loss.. This researcher explained to the caregiver that the manner in which different people, and especially children, deal with their loss depends also on the relationship they had with the deceased. This researcher also explained that most of the times children are more attached to their mothers than their fathers, thus they suffer greatly when it is their mother they lose because of death. This researcher recommended that she should take them for counselling, and if possible she should also try to get some counselling too. I gave them the addresses of the social workers in their area, but also suggested that they should establish if the school has school based support team since this is the team at schools that is responsible for the psycho-social and physical problems that learners experience..

“Although both of the orphans have been diagnosed HIV negative, one of the orphans has a problem of being unable to control passing of her urine”.

This researcher explained to the caregiver that this type of behaviour is common, and can happen to anyone. This researcher emphasised that in some children it may be related to a medical condition, which may or may not be inherited from parents.

However, in some other children it may be a psychological problem due to different causes. For example, it may be due to factors such as abuse, rape, or even a loss of a parent. This researcher suggested that they should go to the clinic where they could be appropriately advised as to what remedy can be given to the girl.

"I have my own children. Although my children have always been having a good relationship with these orphans, there is now some kind of tension. I guess this may be created by the fact that we have to complement the orphans' child social grants from the Department of Social Development and Welfare with own income. This is creating animosity between my own children and the two orphans, because my children complain that they no longer get the things they used to get before the two orphans were adopted".

This researcher suggested to the caregiver that in such a situation she should try to involve her children whenever a decision that affects the two orphans and the whole family has to be taken. This will ensure that they become part of the solution rather than just accepting what they are told. It may even help improve the relationship between her children and the two orphans. The caregiver explained her reasons for the need to supplement the orphans' social grants from the Department of Social Development and Welfare with her own income.

"One of the orphans has to travel long distances to school. Since the child social grant is not always enough to meet all their needs, this orphan has to eat at home. Due to this long distance, his academic and scholastic performance has even deteriorated".

This researcher reiterated her first advice that the caregiver should try to establish if there was any school based support team in the school. This researcher also offered to go with her (grand-mother) to the orphans' schools if she needed her help (also as part of this researcher's advocacy initiatives. It may be possible that such a team does not exist at a secondary school. However, it was this researcher's belief that a solution could be found at the school.

4.2.2.3 Caregiver three's responses questions seven to sixteen

"I do not have any sort of problems with my orphans. In fact my relationship with them is even better than their relationship with their brother who is my partner. I guess it is because I spend most of the time with them. We do have children of our own and their relationship with the orphans is good".

I had an opportunity to talk to the boy orphan and from my assessment it was quite evident that the caregiver was honest about her relationship with the orphans. He spoke highly of his sister, that is, the caregiver. He mentioned that he always tries to help her with the cleaning of the house after school, as well as during weekends. From time to time, he would always say 'my sister', when referring to his caregiver. However, the caregiver was having concerns regarding their future studies.

"One of my worries is that we are unable to adopt the orphans legally due to our marital status".

I reassured the caregiver that this would be thoroughly investigated and a solution will be found regarding the legal adoption of the orphans.

"We are concerned that we may not be able to save enough money to support the future educational needs of these orphans".

I informed the caregiver that their situation is not necessarily different from that of other learners, regarding post-matriculation studies. There are lot of learners whose parents are working, but are still unable to send them to institutions of higher learning. However, there is financial help that these institutions are giving to financially disadvantaged students. I even mentioned that some other institutions are having Foundation Year Programmes, which caters for learners whose academic records were not allowing them to go straight into the main academic programmes. These Foundation Year Academic Programmes are also used by learners who passed their matriculation well, but were unable to register for their desired academic programmes due to financial limitations. I assured her that we should keep in touch so that when the time comes when any of her children or orphans has to go to university, she would be appropriately advised.

"I'm also concerned that since I myself am in my twenties, I'm unable to deal with teenagers, as one of the orphans is a teenager. However, I must give credit to the educators of one of my orphans because they give me moral support. They even give me some coaching regarding ways in which I should relate with teenagers".

I encouraged her to meet with other women in her neighbourhood, where they can psychologically, socially and morally support each other.

4.2.2.4 Caregiver four's responses questions seven to sixteen

"You know, these orphans always make me aware that I am not their biological mother. I also observed that these orphans don't have love for one another and seem to have internal anger and are never satisfied. They give one another such a bad treatment and never want to talk about their parents. In fact four of the orphans were not communicating with the others except themselves. The older ones demand expensive clothes, which cannot be maintained by their social grants. My sixteen-year-old girl orphan is currently attending a school for the delinquent. She was influencing the others to disrespect me, and she is full of jealousy. For example, she has influenced one of the boys to sleep out. The fact that I have to endure seeing one of the orphans rotting in a mental institution gives me sleepless nights".

I assured the caregiver that caring for orphans has never been easy. Their behaviour seems to be common throughout the world. However, with proper psycho-social counselling, they might be able to be helped, and I further suggested that she should consult social workers for help.

"Before the sixteen-year-old girl orphan was sent to the school for the delinquent, she spent most of the nights out. This girl has once been raped while out at night and does not seem to care. She continued sleeping out, and she even boasts that sometimes she sleeps with four different boys. Now that she is at this school, I'm even worried that she might run away from this school. One day this girl even fabricated a story that I had beaten up one of my orphans, when I was actually not at home on the day of the alleged incident. The children were left under the care of my sister. The girl together with one of the educators at a pre-school where this child they allege I had beaten

attends. On my return from my mother's place, I found that the child had been taken away. When I went to the police to open a case, I was locked-up by one of the policemen handling the case of child abuse. After having been given a bail, I found that all the orphans had been taken away to Johannesburg. The children were only returned to me after I had reported the case to the local social workers that were not even aware of the current situation".

"I'm not aware if any of my orphans is HIV positive or has AIDS. Records from the Social Development Services Department do not indicate the HIV/AIDS status of the orphans"

My advice to the caregiver was that she should seek advice from the social workers of whether it is legal to have all the orphans tested for HIV/AIDS. My recommendation was purely based on the assumption that should any of those orphans be HIV positive, at least she or he would get immediate psychological and social counselling and medical attention.

4.2.2.5 Caregiver five's responses questions seven to sixteen

"One of the twins, who is normally referred to as 'small boy' was diagnosed HIV positive. Small boy, like any other HIV infected patient, has to eat fresh foods. Although 'small boy' is recovering well, he still has to attend treatment at Chris Hani hospital. He is not aware of his HIV/AIDS status and keeps asking why he keeps falling sick while his brother's health seems to be good. This is creating a problem for me because I do not know how to break the news to him. He is also hyperactive and thus has to be given proper treatment".

"Big boy, his twin brother, is developing a worrying behaviour. He has become so troublesome at school that I am summoned to the school frequently because of this behaviour. One day I was requested to come to the school because he had missed classes. He was found at a taxi rank several streets from the school. He had to pass two busy roads to get to that taxi rank. Not a single day passes without the twin brothers loosing or misplacing their school uniforms. I have to spend money frequently, to buy twins new uniform and I can no longer take the pain of having to spend money

unnecessarily. Big boy is also beginning to steal money from other children. Sometimes when I send him to the shops, he takes his time. They like very expensive clothes. Although these two boys are giving me hard times, I am still adamant that I will continue giving care to orphans, even in future because it is something that I like doing”.

“I also have my own two children. My own children have a wonderful relationship with these twins”.

4.2.2.6 Caregiver six’s responses questions seven to sixteen

“Our emotional stress relates to the issue of the children’s birth certificates. This creates another problem because the children could not receive child social grants or foster social grants. Home Affairs referred us to social workers to help us solve this problem. After several endeavours, one of the orphans was given her birth certificate. However, her twin brother is still without a birth certificate. We have given up on getting a birth certificate for the other twin. It becomes a problem when they get ill because the social grant is not sufficient to buy them proper medication”.

4.2.2.7 Caregiver seven’s responses questions seven to sixteen

“We experience several problems caused by our orphans. One of the orphans had to leave our place and went to live with my elder sister. He was throwing stones at me and after consulting social workers; it was recommended that he should be placed with another caregiver. At some stage, it was alleged that this boy was living with another man’s wife. He also demanded money from his social grant to buy some movies. When I approached my sister concerning this boy’s behaviour, she refutes my claims. She asserted that she had never received any complaints about this boy, and this created tension among family members. My elder sister also refuted claims that he is smoking and drinking alcohol. However, even neighbours had confirmed that he is in fact smoking and drinking alcohol”.

My advice to the caregiver was that she should work together with her sister for the benefit of the orphan. I emphasised to her that if they cannot win him over, they might

lose him forever. In many instances these kinds of children escape the family safety net and end up in the streets.

"I am even suffering abuse from my family members, and they are accusing me of building my house with the orphans' social grants. Although I have fourteen siblings, most of them refuse to accept the two orphans. This tension has led me refusing to sign for this boy's social grant as long as he is still living with my sister. I don't want to sign because I do not have control over the money. I would rather prefer that my sister rather sign for the social grant".

4.2.2.8 Caregiver eight's responses questions seven to sixteen

"Insufficient social grants are one of the things causing problems for me. I am worried that if one of the orphans should die, I will have difficulties burying the child. My other main concern was that once a child has finished matriculation, it might be difficult to send that orphan to the university to pursue further his/her academic studies".

I assured the caregiver that most universities have student financial aids. These are given to deserving students, especially those from disadvantaged backgrounds. However, once a student completes his or her studies the money must be paid back. The reason for this is because other students with financial constraints have to benefit from the same financial aid.

"Most of my orphans want expensive clothes because they claim that they receive social grants. I must admit that the problems that the orphans face also affect me. One of the orphans was becoming naughty. He steals from other children and when he is asked why he had done so he just keeps quiet. I normally allow my orphans to express their feelings. I am happy that I am looking after these orphans and they had brought happiness in my life since I have separated from my husband. My wish is to see them succeeding in life so that they can also make positive contributions towards their communities. I have children of my own, and there doesn't seem to be any relational problems between my children and the orphans".

"I would wish that we (caregivers) could be provided with training so as to handle pressures of care giving. I was having a problem of having to talk to one of her orphans about his behaviour. This boy was far ahead of his age since he knew things that even his age group were not aware of. Before he was taken care of, he used to mix with the wrong people because he was a street child. Another problem I am facing is that of an orphan who wants to know about his biological parents. I am unable to tell him about his real mother because I do not know where the mother is. Another of my orphans was adopted while I was still married to my husband. This orphan is creating problems for me since the child does not understand why we are no longer living together. The child tries everything to bring us together. He even asks my ex-husband to attend to his school problems or events. If the school requires a guardian, he would tell my ex-husband to go and attend to the matter.

4.2.2.9 Caregiver nine's responses questions seven to sixteen

"Our emotional problems emanate from lack of prior planning by the orphans' parents, because their parents did not leave any legal "will" (testament), which clearly stipulates how the adoption should be conducted and who should take care of the children. However, we still maintain that traditionally, the closest relatives of the children's father should be caregivers. This is to ensure that the orphans are taught their father's customs and traditions, which are very important for their upbringing. We were shocked to discover after the burial of the orphans' mother that their mother had given them to the care of her younger sister without the approval of their father. Our concerns relate to the person whom their mother has chosen to take care of them. She lives far away from their actual home, and what makes matters worse is that she has adopted a different culture. The children will have to change their customs and adapt to this foreign culture. You know, with us Africans, anything can go wrong with the children's lives. Once they start becoming sick, it might be related to our ancestors not being happy and thus punishing the poor orphans. In this instance, the people who would be blamed for these sicknesses would be us. We may even be punished ourselves, for allowing these children to be given to this foreign culture. The trouble is that, when these children start having problems, and their money is gone, they would come to us".

"All what this other family is interested in is the financial gains they will have out of the orphans' situation. We are perturbed by the fact that the orphans' parents' belongings, for example, cars, furniture and the house will soon be auctioned without our concern. Their clothes and some furniture have already been shared among their mother's siblings. We are really worried that this will create a situation whereby these orphans will not have a home and may even not have enough money to further their education".

I suggested to the caregivers that they should approach a lawyer immediately to stop all the auctioning of the orphans' heritage. They should even see a social worker as soon as possible because they too, have powers to stop that, as they have access to the magistrate courts. The caregivers indicated that in fact, the almost auctioning of the house was cancelled by the social workers by demanding the keys to the house.

"Our relationship with the orphans is fine, as far as we know. We also have our own children, which are two older boys. The relationship between these orphans and our own children is normal and cordial. However, we are worried that the existing squabbles between their mother's relatives and us could sever this healthy relationship. We are not even sure as to how far their mother's influence on them is, since there seemed to have been some bad blood between their parents. The father was working away from their family and they used to spend most of their time with their mother. Their mother was accusing their father of cheating on her, and their father was also accusing their mother of cheating. This has even led their father to suspect that he did not father their son. Their mother did not allow them to have frequent visits to their father's uncles and their aunt, but had frequent visits to their mother's relatives. This might have somehow impacted on the relationship between the orphans and their children. However, we still maintain that the orphans are relating very well with their father's relatives, and seem to enjoy their company".

I indicated to the caregivers that it was important that the orphans were relating well with both families. Thus, they (caregivers) should ensure that what ever happens after the conclusion of the adoption process, the orphans have access to both families. Their relationship with their father's relatives is as equally important as their relationship with their mother's relatives.

"Although the orphans' state of health seem to be excellent, we do not know whether they are infected by HIV or have Aids. We are not aware if the orphans have been tested for HIV/Aids. You know, for us it is just not the question of caring for HIV/Aids orphans. However, it is our obligation to care for our brother's children because this is necessitated by our customs and beliefs. We believe that if we do not do this, trouble will befall us, and even the orphans will experience problems in their lives for not following their father's customs".

4.2.2.10 Caregiver ten's responses questions seven to sixteen

"Generally, I do not seem to have any major problems. My problem seems to be with my sister's attitude. She is stubborn and does not take advices. She appears to be having anger and she is very moody. She is taking her frustrations out on other people. For example, she is not relating well with my boyfriend who is giving us financial support. Although my sister is repeating grade 11, her performance does not seem to be improving. My sister was one of the top learners before the death of my mother. However, her performance dropped drastically since her death. I get tremendous support from my relatives".

My advice to the caregiver was to have patience with her sister. She might not be as strong as she (caregiver) is. I pointed out to her that the loss of the loved one might have different impact to different people affected by the same loss. I recommended that they should both see a professional counsellor, even if it may not necessarily be a social worker or psychologist. I gave her a list of organisations that deal with issues relating to counselling and support. I even suggested that they could even consult with their Pastor at the church, or someone she or her sister has trust on.

"I suppose I'm HIV negative, although I haven't tested. I take precautions when having sex with my boyfriend. I really don't know my sister's HIV/AIDS status because I feel that it's a personal thing".

Although I did not want to probe the caregiver further about what she meant by precautions, I nevertheless encouraged her to take the HIV/AIDS test. I advised her to befriend her sister, so as to win her confidence to a point where they could confidently discuss issues of life, including sex. I pointed to her that, although most people believe

that it is safe to use condoms, this method of protection is not full proof. We still need to take frequent HIV/AIDS testing.

4.2.2.11 Caregiver eleven's responses questions seven to sixteen

"My relationship with my brother is quite good. The fact that we were left to fend for ourselves has strengthened our friendship. We realise that since our grandmother might also die because of her age and ill health, we would have no other close relatives to care for us. We have been deserted by those we considered blood relatives since the death of our mother. The fact that I have sacrificed my happiness and career to go and find a job at a very early age has made my brother to appreciate my efforts. This has even created a very strong bond between the two of us".

"As mentioned earlier, I also have two children of my own, and the relationship between my children and my brother is excellent. My brother has since taken the responsibility of looking after my children since I do not live with them. My brother has become their role model, and this makes me confident that they will become better citizens as long as they are closer to their uncle. Since our relatives abandoned us, there isn't much of a relationship between those relatives and us. However, this doesn't mean that there is any hatred between my relatives and us since we never communicated that much. Both my brother and I have excellent health conditions and are free from HIV/Aids. Because of our sufferings, I would encourage other people to be caregivers. However, I'm worried that with the scourge of HIV/Aids, HIV/Aids will affect most families and the situation is very scary".

4.2.3 Questions seventeen to nineteen investigated the health impact of caring for AIDS orphans on caregivers

These questions were based on the researcher's assumption that caring for HIV infected or affected orphans could endanger the lives of those carrying for them, if appropriate precautions are not taken. However, if caregivers are themselves sick, they may endanger the lives of those they are taking care for. The caregiver participants responded to questions such as:

- Could they give an account of their own health status?

- How often do they attend treatment for their illness?
- Did this illness start before or after caring for these two orphans?

The following responses are accounts of the caregiver's health conditions:

4.2.3.1 Caregiver one's responses to questions seventeen to nineteen

"I do not suffer from any serious illnesses that may be detrimental to the lives of those I'm caring for. However, just like any normal person, I do have some health problems that come and go".

4.2.3.2 Caregiver two's responses to questions seventeen to nineteen

"I have high blood, but it has been troubling me for some time even before I started caring for these orphans. However, having this extra burden of caring for two orphans without adequate financial backing might not help my health condition".

4.2.3.3 Caregiver three's responses to questions seventeen to nineteen

"I am healthy, except when I'm suffering from flu or having a headache, which are illnesses that most people are experiencing".

4.2.3.4 Caregiver four's responses to questions seventeen to nineteen

"Apart from the emotional stress these orphans cause me, I am healthy".

4.2.3.5 Caregiver five's responses to questions seventeen to nineteen

"I do not have any serious health problems. I do get sick occasionally, but I guess it's normal".

4.2.3.6 Caregiver six's responses questions seventeen to nineteen

"I suppose the illnesses I may be suffering from may be related to my age. I do get medication for my illness".

4.2.3.7 Caregiver seven's responses to questions seventeen to nineteen

"I do not have any serious health problems other than the stress my family is causing me".

4.2.3.8 Caregiver eight's responses to questions seventeen to nineteen

"My health is well at the moment".

4.2.3.9 Caregiver nine's responses to questions seventeen to nineteen

"I don't have any problems with my health".

4.2.3.10 Caregiver ten's responses questions seventeen to nineteen

"I and my wife don't have any problems with our health".

4.2.3.11 Caregiver eleven's responses questions seventeen to nineteen

"My health is fine".

Follow-up questions were not necessary in the case of caregivers three to eleven because they indicated that their health conditions were normal.

4.2.4 Questions twenty to twenty-seven investigated ways in which caregivers are experience financial problems because of their caring for AIDS orphans

The following questions were used to investigate ways in which caregivers experience financial problems because of their caring for AIDS orphans

- How many people are working in the family?
- Does the family have any other source of income for caring for AIDS orphans?
- Does the family receive any social grant from the Department of Social Development and Welfare?
- What are the basic needs of the orphans?

- Is the social grant from the Department of Social Development and Welfare sufficient for all the two AIDS orphans' needs?
- What else does the family use the social grant from the Department of Social Development and Welfare for?
- Are the two orphans aware of the social grant they receive from the Department of Social Development and Welfare on their behalf?
- If orphans are aware of the social grant from the Department of Social Development and Welfare, are they not demanding to have full control of the usage of this grant?

Since unstructured interviews were conducted for this study, as said above, the questions were not asked in any particular order, but were dictated by the responses of the caregiver. The following are the responses of the lady caregiver:

4.2.4.1 Caregiver one's responses to questions twenty to twenty seven

"Although both orphans are receiving social grants, in the form of child social grants, initially through their grandparents and later by me, this grant was stopped because of family fighting. I then approached my father to inquire about the stoppage of the grant. However, my father suggested that his sister might have stopped it, as she also wanted to be given a share from that grant. During the stoppage of these grants, these orphans were financially supported by 'tjhelete ya letheke' I receive for my own three children. However, these child grants were restored after your (researcher's) intervention. It was very difficult to cope because the child grant and 'tjhelete ya letheke' were the only two sources of income for the family since both my husband and I were unemployed". 'Tjhelete ya letheke', as is commonly referred to in our township language, is the child grant given to single-parent family or unemployed people. These child grants for the two orphans were finally restored through this researcher's intervention, by approaching the social workers for assistance.

"My husband is suffering from tuberculosis. I used to work as a car guard in town; however, I had to sacrifice this income because of the extra care that the two orphans needed. Although I was happy to have the child grants for both orphans restored, this created another problem. On the day of collecting the grant, the boy orphan does not

want to attend school. Instead he demands that he accompanies me, so as to buy him whatever he wants. He has become so arrogant and only thinks about himself. This creates tension between us, besides, this grant is not even enough to maintain the budget for his expensive food, which has to be fresh all the time". The caregiver was asked if she ever shares her frustrations with anybody, since she mentioned earlier that she never informs her husband about any problems relating to the orphans' health or behaviour problems. "I find comfort from the assistance of my sister, who also looks after the orphans when we are in financial distress. The child grant for the orphans is used mainly for the orphans' food. A bulk is consumed in their food since because of the boy orphan's HIV/Aids status he has to eat fresh food and he also has to eat frequently. The social grants are not even enough to buy them food and some medication, whenever is necessary. I have to supplement these with the 'tjhelete ya letheke' I receive for my own children".

4.2.4.2 Caregiver two's responses to questions twenty to twenty seven

"I am receiving an old-age social grant, which I'm using to support my children and even the two orphans. However, I am also receiving the child social grant for the two orphans. I had initially applied for foster social grants, but was told that this type of social grant no longer existed. I persisted applying for foster social grants without any success because my requests were repetitively turned down. These social grants are not enough to even help the other orphan with his transport fees to school, as it was further away from home. The grant was mainly used for food and clothes. I even use my own money to pay for their karate lessons as she encouraged them to play sport. I'm worried that this has resulted in anger within my own children, as they are no longer getting things that they used to get".

This researcher assured the caregiver that she would do her own investigation regarding the foster social grant applications. After this researcher had approached the social workers in another region, she was informed that it was not true that foster social grants do no longer exist. The advice that this researcher was given was to find explanation from the Department of Social Development and Welfare. This researcher is still pursuing this matter as of the time of completing this manuscript.

“Both orphans are aware of the child social grants I receive on their behalf. However, I never experienced any problems from them, regarding the usage of their social grants. I guess it might be because they are aware that I’m supplementing these social grants with my own money”.

4.2.4.3 Caregiver three’s responses to questions twenty to twenty seven

“My partner does not have a stable job, but do some temporary or contract jobs. His jobs are not paying that well. However, the money that he brings home does help us to give the two orphans and our own child a great deal of support. We do survive on that small income even though it sometime becomes difficult to cope. Although I’m currently unemployed, I am receiving some training on catering”.

“The two orphans receive child grants, but those grants are given to my partner’s stepfather on their behalf. My partner’s stepfather does not always give the money to us as caregivers. These child grants are not even sufficient to meet the orphans’ needs. We use the grants mainly for food, clothes and other necessities. We don’t want to apply for foster grants so as to avoid family squabbles. The two orphans do not mind as to how I use their grants, in the event that we do receive them from their grandfather”.

I made the caregiver aware that it was illegal for the orphans’ grandfather to withhold their social grant. In fact, I suggested that they approach social workers to arrange for those grants to be given to them as they are taking care of the orphans. I also explained that if the situation continues, where the grandfather does not forward the money to their rightful owners, and should this be reported to the social workers, the grant would be stopped.

4.2.4.4 Caregiver four’s responses to questions twenty to twenty seven

“I get foster social grants for my orphans. However, the money is not enough to meet all their needs. The older orphan demands expensive clothes, which cannot be accommodated by the foster grant. I even had to take this older orphan to the social workers, so that they can explain to her (orphan) how the money should be used. The orphan wanted to use her foster grant for things like expensive cell phones and other

unnecessary items. I do not have any other means of income apart from the foster grants I receives. I really appreciated the financial support I get from my relatives”.

“The way I understand the job I’m doing is that caring is like a fulltime job, which must be properly remunerated. Foster grants or child grants are mainly for the purposes of giving support to the affected children. However, the people giving care to these orphans must be paid to care for those orphans. There is another problem that I will be facing in future, regarding the youngest orphan. This orphan is due to attend pre-school where she will be paying monthly school fees, which are sometime exorbitant”.

“Two of the younger orphans are still wearing napkins and live on powder milk, which are very expensive. Because I cannot afford to buy all my children clothes at once, I usually buy for one or two children and put those clothes safe until I am able to buy for all of them”.

4.2.4.5 Caregiver five’s responses to questions twenty to twenty seven

“I receive monthly foster grants for the twins. I do not have any other means of income. The grant is mainly consumed by freshly prepared food for one of the twins who is HIV positive. I have to source other funds from anything I can do or sell to supplement the foster grant. My own son is also supporting me financially as he is employed. He also sells clothes during his spare time to supplement his salary. The total transport fees for the twins are amounting to R500 per month. We also spent money on transport to Johannesburg for medical treatment. This is the psychological therapy and medication for the HIV positive twin. This twin is hyperactive and he has to attend treatment at Chris Hani/Baragwanath hospital”.

“I often have to buy school uniform because they frequently lose their uniforms. The twins are also very selective on the choice of clothes I have to buy. They like classy clothes, which are more expensive. But I blame my son for this because since he is also selling clothes, he buys the twins these expensive clothes when he has some extra cash”.

"I could not have afforded the costs for the medical treatment the HIV twin receives from the hospital. I am, however, delighted that the doctors who were responsible for the treatment, sourced funding from donations they organised for the child. I allowed them to put the photograph of the HIV positive twin in newspapers and TV to source funds from the public. However, I am not happy that I was not informed how much donations the doctors were able to collect. It is my belief that the twin's poor health (HIV positive) necessitates increase in the foster grant. I am also not entirely happy that they (caregivers) are not being compensated for caring for orphans. I propose that the government should give us bonuses at the end of the year".

I asked the caregiver whether the twin's desire for expensive clothes was not because they were aware that she was getting foster grants for them.

"These twins are spoiled, and besides, we have such a wonderful relationship. There is nothing indicating that they might be behaving this way because of their knowledge of the foster grants".

4.2.4.6 Caregiver six's responses to questions twenty to twenty seven

"I get an old-age grant. I also receive a child grant for one of the twins, but do not get anything for her two sisters. The problem is that the two sisters are not having birth certificates, which led me to not being able to apply for their identity documents. Both my old-age grant and the twin's child grant are not sufficient to support the family. The twin's sisters are at a Secondary School, which is not quite close to their home. This necessitates them to take lunch packs to school. However, it is not always possible to do this, as I do not have any other means of income. I cannot even buy them the proper school uniform like other learners. When they get ill, I am unable to get them proper medication or send them to the doctor".

I have made it my first priority to try to investigate the problem and have promised the caregiver that I will try to get in touch with some people I know from Home Affairs. These people have solved some of the problems I had in the past, and am quite sure that they would be able to help with this particular problem.

4.2.4.7 Caregiver seven's responses to questions twenty to twenty seven

"We receive a child grant for the orphan. I also work as a domestic worker. My husband is a contract worker, and the job is not secured. Both my child and the orphan are choosy and like expensive food, which I cannot afford to buy. Before the orphan's brother was moved to my sister, he used to demand his grant so as to go to the movies. But I emphasised that the grant I receive on his behalf is used for food and clothes for him. However, I maintain that the grant is not enough for all the orphan's needs".

4.2.4.8 Caregiver eight's responses to questions twenty to twenty seven

"I receive foster grants for all my orphans, that is, six orphans. Although I am unemployed, I have my own child who is employed and thus assists me financially. However, foster grants are not sufficient since two of my orphans are HIV positive. I have to allocate some portion of the grant for their medical expenses. In fact, one of the two HIV positive orphans is a baby who has to wear napkins and drinks powdered milk. The foster grant I receive for this baby is not sufficient for all these. I cannot afford the expensive medication and food I have to provide to these particular orphans. However, I am relieved that the other HIV positive orphan still has a good relationship with my ex-husband. When the orphan needed some financial assistant, the child would approach my ex-husband for help. This is because, as mentioned earlier, the orphan was adopted while the two were still married and the orphan was still a baby. Thus the child still regards my ex-husband as a father. The older orphans demand very expensive clothes, which cannot be supported by the foster grants".

"I'm worried that it may not be possible to give good care to the orphans who will be 18 years old since the grant will be automatically stopped. This may ultimately stop the orphans from pursuing their studies at tertiary institutions. I wish that the foster grants may be increased so as to keep with the financial demands related to care giving".

4.2.4.9 Caregiver nine's responses to questions twenty to twenty seven

"As I mentioned earlier, I'm a full-time student. I do not have any other source of income. I receive a foster grant for my sister. However, I'm worried that since my sister is seventeen years old, this grant will be stopped once she turns eighteen years.

However, at least according to my understanding, my sister will continue receiving the grant as long as she is still a learner. This foster grant is not sufficient for our needs, but I am delighted in the support I receive from my boyfriend. My boyfriend buys me food and clothes. I also get a student loan to pay for my tertiary studies, but I can feel the financial burden. I must say that managing my sister's grant is very difficult as I have to convince her that the way I'm spending the grant is the only best way, just to ensure that we survive".

4.2.4.10 Caregiver ten's responses questions twenty to twenty seven

"Our family is financially viable. You see, even if wife is not working, I can take good care of my family because I'm the manager in the company I work for. Besides, since the orphans' parents were both employed, I do not foresee anyway the orphans would have financial problems. The orphans' mother was an educator, while their father was an employee of one of the mining companies. In fact, their father held a senior position in the mine. I can assure you that if the orphans' estate could be handled properly, these orphans will never have any financial difficulties in their future. Right now, we have not even started with the process of trying to gain legal custody of the orphans. We are currently still battling to protect the orphans' estate since it has become evident that the person whom the orphans' mother has requested to care for her children is only interested in her personal gains out of this situation. Our intention is to use our own finances to cater for the orphans' immediate needs, while keeping the orphans' money intact within the estate. We prefer that the orphans rather use the money for their future tertiary studies. We would also like to see these orphans starting their adulthood without incurring any financial debts".

My immediate reaction when the caregivers were saying that they would rather use their own money to support the orphans, was the tension this might create between the caregivers' own children and the orphans. I highlighted this fear to the caregivers. However, they assured me that they would treat the situation with utmost care because they value their children's welfare too.

4.2.4.11 Caregiver eleven's responses to questions twenty to twenty seven

"I work as a domestic worker and I do not receive any child or foster grant. However, since my brother lives with my grandmother, she also uses her old-age grant to support my brother and my own two children. I send them money periodically, as I cannot afford to visits them. The money would be used-up by the high transport costs. Most of the money I send home is used for my brother's educational needs. Some portion of the money is used for food and clothes, while the rest is used for their daily necessities such as medication when they are sick, transport and other bills. I'm also getting some financial support from my current boyfriend. However, I really do not want to develop a habit of requesting financial assistance from my boyfriend. You see I do not want to end up becoming a slave to my boyfriend or feeling obliged to return favours to him. Fortunately my brother understands our financial predicament, and thus does not have any unnecessary financial demands".

Although initially I could not understand why the caregiver was not receiving a child or foster grant, it became clear as the interview progressed that she was coming from a neighbouring country. This automatically disqualified her from applying for a foster grant since she was not even a refugee.

4.2.5 Questions twenty-eight to thirty-six investigated the impact of AIDS orphans caring on the social life of caregivers

The following questions investigated the social impact of AIDS orphans caring on the social life of caregivers:

- Are any of their AIDS orphans attending school?
- Do their AIDS orphans get any support from the schools where they attend?
- How is the relationship between them and their neighbours?
- Does this relationship affect the orphans in their care?
- Do orphans under their care have friends in the community?
- Are the orphans in their care having a good relationship with the other community members?
- Is the community aware of the HIV/AIDS status of orphans in

their care?

- What kind of support do caregivers get from their community?
- Are they aware of any support groups in their community?

The following responses were obtained regarding the social impact of caring for AIDS orphans.

4.2.5.1 Caregiver one's responses to questions twenty eight to thirty six

"I do not know how to express my feelings for what the educators of one of my orphans did for him (orphan). For the fact that I was requested to come to the school to discuss the problems experienced by one of my orphans, even before I became the caregiver, makes me believe that the orphan is attending the right school. My orphan's educators requested me to take him into my care. In fact, some of his educators even assisted me with his school uniform and other clothes. Other educators are giving my boy orphan vegetables and fruits to take home. I was informed that one of his educators also informed the principal about the HIV/AIDS status of my orphan. However, the principal did not seem to care. The concerned educator then requested the people responsible for the school feeding scheme to include my boy orphan in the list of children qualifying to receive food from the feeding scheme. The school is even collecting old and unused clothes for vulnerable children and orphans, and my orphan also benefited from that scheme". After further investigation, it was discovered that the clothes were actually collected from other educators, as well as from the surrounding community, where the school is situated.

"I must confess that the community where I live does not know of my boy orphan's HIV/AIDS status, and even his friends are not aware that he is HIV positive. I have kept it secret to even the orphans himself. I told him that he was suffering from tuberculosis. I do not have any problems with my neighbours, but I just don't want them to know about my boy orphan's HIV/AIDS status for his own sake because it is difficult to tell him what causes his illness". It was clear that the reasons for the caregiver not wanting to inform the community about the HIV/AIDS status of her boy orphan, was not because of the prejudices she thought the family might suffer from the community.

“Although my HIV positive orphan was supposed to fetch powdered milk from the community clinic, he does not always do this. He was also invited to collect food parcels from one of the community centres. For example, he was expected to get breakfast in the morning on his way to school. After school, he was supposed to collect lunch on his way home. However, this boy did not always collect these food parcels. I could fetch the milk and the food parcels for the boy, but this is not allowed”. I (researcher) then advised the caregiver to accompany the orphan to the clinic and community centre to ensure that the orphan does get his provisions. It was possible that the clinic and community centres thought that when the caregivers collect these provisions, they might not reach the people they are meant for.

As mentioned during the interview with caregiver one, it was found necessary for me to intervene as part of advocacy in some instances. However, since I did not want to be seen as interfering in family affairs, I felt that it might be necessary to interview the grandparents in order to hear their side of the story. Some serious allegations were levelled against them, which were also confirmed by one of the boy orphan's educators. The educator was also interviewed so as to make the orphans' cases stronger, for speedy resolution.

4.2.5.2 Caregiver two's responses to questions twenty eight to thirty six

“As I mentioned earlier, both two orphans are attending school. In fact, I noticed that the orphans were struggling with their studies. I then went to the schools to enquire about their academic and scholastic performance as I was becoming worried that they may be mixing with the wrong people. However, I was assured that they seemed to be good children. The educators cited the family situation as a possible reason for the orphans' academic and scholastic poor performance. They argued that the orphans might be aware of the family's poor financial status”.

“The absence of feeding schemes at secondary schools might also contribute to the poor performance of one of these orphans. I suspect that the long distance that he has to travel to have lunch at home might actually contribute to the academic and scholastic poor performance”.

"Initially the community was not supportive, especially when the two orphans' mothers died. Most people suspected that the causes of their deaths might have been HIV/Aids related. However, I am happy that the community is now very supportive. I suspect that the sudden change of attitude from the community suggests that it is a sign that HIV/Aids is now becoming acceptable, probably because it's spreading and more people are educated about it. I also believe that the governmental and non-governmental HIV/Aids awareness campaigns may also contribute to the acceptance of HIV/Aids".

This researcher suggested to the caregiver that the change of attitude among the community members could also be due to influences and more education on this pandemic at schools. Most schools are expected to touch on health issues including HIV and AIDS, as well as the constitutional rights of even those infected or affected by HIV and AIDS. This researcher also pointed out to her that children have as much influence on parents', community's and educators' lives as we have on their lives. For example, during parents', community's and educators' interactions with them, there are lessons that parents, community and educators receive from them, especially since they are expected to help them with their homework.

"I'm not aware of any community support groups in my area. I am even thinking of starting a support group in this area, and wish to take care of other orphans if the government could assist me financially. I used to receive grocery from the social workers, but it was stopped without any reason given".

This advised the caregiver to approach the social workers in order to find reasons for the stoppage of the grocery. Furthermore, my suggestion was that she should go to the Department of Social Development and Welfare to find out if there are no other forms of assistance that could be given to her.

4.2.5.3 Caregiver three's responses to questions twenty eight to thirty six

"Both of these orphans are attending school. In fact, I receive valuable support from the orphans' educators. They are advising me about how to deal with teenage children because I'm in my twenties and lacked skills of handling teenagers".

"I also get support from the community. However, I find it funny that the only bad influence that the orphans were getting was from a relative. The orphans are given food parcels from the community centre. Apart from the food parcels, the centre is also providing sporting activities to keep orphans busy. This also helps orphans take their minds off their problems. They are also receiving training in different subjects ranging from different school subjects to social issues affecting their lives".

"I have never heard of a situation where my orphans have been discriminated against by anyone from the community. They have friends in the community, and you can ask them if they ever suffered any prejudices from neighbours or their friends".

The orphans spoke well of their neighbours and their friends. However, I must indicate that the boy orphan dominated the discussion with the orphans. The girl orphan seemed to be shy, even though I suspect that she might have been respectful of her brother since she was younger than him.

"Both orphans are healthy and have never been diagnosed HIV positive. I guess this may be one of the contributing factor in the healthy relationship we have with the neighbours".

4.2.5.4 Caregiver four's responses to questions twenty eight to thirty six

"There is lack of support groups within our community. There was only one event organised by a non-governmental organisation. However, the event was limited to a maximum of two children. This implies that those caregivers who are caring for more than two orphans, like me, are unable to enjoy full benefits. This meant that we have to sacrifice some orphans. There many support structures in Johannesburg than there are in Vanderbijlpark. This lack of support structures might even be contributing to the lack of discipline displayed by most of the orphans".

"Most of my orphans seem to be doing well at school, except the one who was transferred to a special school, that is, the school for the delinquent".

"My relationship with my neighbours is not good. I suspect that my neighbours might be having a bad influence on my orphans. For example, when I rebuke the orphans when they are misbehaving, they tell me that I'm not their biological mother. I maintain that this could only have come from the influence of my neighbours. In fact, on one occasion I was accused of beating one of the children. This occurred when I was not even at home and the children were under the care of my sister, who is also a caregiver. One of the educators had even arranged with the Johannesburg social services to take this child in my absence. Upon my return, I went to the school to enquire about the child's disappearance and was told that the child had complained of the beatings from me. I was shocked to find the child at the school. I then went to report the matter at the local police station, but was shocked when one of the police officer said to the other one who was taking her statement that I was the suspect. I was immediately taken to a police cells. When I enquired why I was being held, I was informed that one of my orphans had given a statement to the effect that I have physically abused the other orphan".

"During my imprisonment, all the children were taken away from me. What was even painful was that the police were making up all this with the educator at the crèche where my orphan was attending. The local social workers were not even aware of the problem. My sister informed the local social workers, and upon their intervention, I was released from the police cell. The social workers informed me that they have been receiving calls from my neighbours that I was abusing my orphans".

4.2.5.5 Caregiver five's responses to questions twenty eight to thirty six

"It's my suspicion that the neighbours might be having a bad influence on my orphans. One of the twins once said that I was not her real mother, when I tried to punish him for misbehaving".

"I'm getting a lot of support from the orphans' school. I even reported the other twin's bad behaviour, as well as his brother's HIV status to the school principal. In fact, the school principal is very supportive and considerate of the HIV positive orphan. This orphan could see the principal anytime he feels like. However, the behaviour of the other twin is not very good. I would be called to the school whenever he has misbehaved, but the educators understood her predicament. I would also be called to the school to collect

the lost uniform. The school has also organised a psychologist for to help my disruptive orphan. The psychologist offers these sessions at school, to help me reduce the transportation costs”.

“I doubt if my neighbours are aware of the HIV/AIDS status of the other twin. I don’t normally talk with them because of their attitude”.

I advised the caregiver to find a way of trying to make peace with her neighbours, and if possible I could assist. She could even talk to the social workers and ask them to act as a buffer between her and neighbours. I emphasised that it was important to endeavour to change other people’s attitudes about certain prejudices for the sake of our children.

4.2.5.6 Caregiver six’s responses to questions twenty eight to thirty six

“I am not experiencing any problems with my neighbours. The orphans are also receiving support from their schools. However, I’m despondent about the treatment I’m receiving from the social services department regarding my endeavours to get three of the orphans’ birth certificates. Home Affairs was referring me to the social workers, but when I approached the social workers, I would be sent back to Home Affairs. I have even given up on trying to get these birth certificates”.

“None of the orphans is HIV positive or has AIDS”.

4.2.5.7 Caregiver seven’s responses to questions twenty eight to thirty six

“I must acknowledge that I am receiving tremendous help from the social workers. For example, they advised me to ask one of my family members to take care of one of the problematic orphan. I also reported the bad behaviour of the other orphan to social workers, and they were supportive. I never received any complaints from the school where the orphans attended. According to my understanding, the orphans seem to be doing well at school. My relationship with my neighbours was never affected by the caring of these orphans. My neighbours even reported the bad behaviour of the orphans to me”.

4.2.5.8 Caregiver eight's responses to questions twenty eight to thirty six

"I have problems with my neighbours who seem to be influencing my orphans, and this is evident from their bad behaviour. For example, the neighbours are asking the orphans if I am receiving foster grants for them. These neighbours would even send my orphans anywhere without my consent. When I approached them to discuss this issue, the neighbours would tell me that those orphans are not my children. This suggests that they would do as they wish with those orphans. I allow my orphans to express their feelings, and was open about discussing their grants with them. I believe that because of bad influence from neighbours, the orphans are demanding expensive clothes because they know that they receive grants. I want to acknowledge that I am receiving great support from the social workers. However, I am adamant that caregivers are not receiving proper training regarding care giving. I propose that they should be given workshops on how to give the best care for their orphans".

4.2.5.9 Caregiver nine's responses to questions twenty eight to thirty six

"I and my sister do not have any sort of problems with other community members. However, whenever I experience problems with my sister I usually consult relatives for counsel. I have never voluntarily consulted social workers regarding my problems. But we only meet social workers when we are invited for some events".

I encouraged the caregiver to find any support group in her neighbourhood. It was critical that she meets with other people who might be experiencing the same problems as the ones she experiences. I emphasised the importance of such support structures because they empower caregivers with some survival as well as life skills to handle problems of care giving.

4.2.5.10 Caregiver ten's responses to questions twenty eight to thirty six

"We do not experience any problems with our neighbours. In fact, we relate very well. Besides, family support structures are very strong, and thus the orphans find comfort within the family. We are getting support from the social workers to gain full adoption of the orphans. Even the attempt by the orphans' uncles and aunts from their mother's side to auction the house was quashed by the social worker. Although community

support groups are important, we are well connected and have access to counselling services within our legal services organisation. Services such as legal advises and trauma services are offered. These orphans are active members of their community. For example, the boy orphan is currently a member of a local football club. The club was very sympathetic towards his loss, and had ensured that he gets whatever help he could. I really doubt that these orphans are experiencing any discrimination from neighbours, as they were aware about the causes of the deaths of their parents”.

4.2.5.11 Caregiver eleven’s responses to questions twenty eight to thirty six

“I have never had any contact with the social services because I do not know how to go about doing that, and besides, what makes it difficult is that I’m not even a citizen in this country. We don’t receive social grants in my country. I welcome the positive feedback I’m getting from my brother’s school. Although the community my family lives in is poor and thus cannot assist them financially, I cherish the moral support they give to my family. I am thankful that our neighbours have never discriminated against my family. You know, my boyfriend has proposed marriage but because I have the responsibility of caring for my brother, who is still at secondary school, I could not accept the proposal. Although my boyfriend is also from another country, he has acquired South African citizenship. Due to my grandmother’s poor health conditions, I might have to take full responsibility of my brother. Although I have discussed my predicament with my boyfriend, who seems to be sympathetic and accommodative, I am still reluctant to place my brother’s responsibility on my boyfriend’s shoulders”.

I suggested that the caregiver should discuss her brother’s situation with her boyfriend and see how he would react. As I write, the caregiver has informed me that her boyfriend has stopped asking her about getting married. They are however, still seeing each other. She acknowledged that she was getting frustrated now that her boyfriend is not talking about marriage. She is not even sure whether or not her boyfriend is committed to their relationship. I advised her to be patient since that kind of a decision is quite difficult and important to make in a short space of time.

4.3 RESPONSES OF GRANDPARENTS (N=2) OF CAREGIVER ONE'S ORPHANS

As mentioned earlier, this interview was necessitated by my involvement in trying to help restore the grant for the orphans. The caregiver alleged that her parents could have stopped collecting it since it is their responsibility to do that. However, her parents told her that it might have been his sister since she wanted to be given some money from these social grants. The following questions (see Appendix Schedule 2) were asked in order to investigate some of the allegations, as well as to ascertain some of the information given by the caregiver, which were relating to the welfare of the boy orphan:

- Can you give me some background relating to the orphan's parents?
- What was the cause of their mother's death?
- Did she attend any support group meetings before she died?
- Are any of your grandchildren having health problems?
- Do you know what could be causing these illnesses?
- Is the orphan aware of the cause of his illness?
- Is he getting any treatment for his illness?
- How is your relationship with the orphans?
- How is your relationship with your neighbours?
- How is your relationship with your children?
- Do you get any support from the community?
- How is your grandson performing at school?
- Is there any support he gets at school?

The questions were also not asked in any specific order, but were dictated by the responses given by the participant. The following responses were obtained from grandparents:

"My daughter, that is the two orphans' mother, left with her husband for Polokwane and when she came back after some time she was ill. However, she did not say how long she has been ill. The two orphans' mother was fully aware of her illness before she died. Her younger sister usually accompanied her to the clinic for treatment. I was also called at the clinic to be informed about her illness. Moreover, I would see her meeting

with other patients having the same illness, whenever she attends treatment. My daughter was attending support groups at the clinic before she died". There were no support groups in the community. The two orphans' grandparents refused to state the exact type of illness her daughter was suffering from. However, it was evident from her responses that she knew what caused the death of her daughter. It is usually obvious that people attending support groups are associated with HIV and AIDS.

"The boy orphan is suffering from tuberculosis, which I think he received from his grandfather. You see, his grandfather is also suffering from tuberculosis and I think he might have infected him. His grandfather is not keen to tell the boy about the real nature of his (orphan) illness. He also has mouth and nose ulcers. He was never ill when he was still small. However, he started getting ill when he was in Grade two. He is getting medication for his tuberculosis and he eats properly, although at his own time. The child must be given nutritious food and although he eats, he sometime brings his lunch pack after school". The grandparents seemed to be very touched when they were talking about their grandson's health problems.

"I'm affected by his illness and wish that it could just disappear. I'm despondent because the boy gets everything he needs, but keeps getting sick. His sister is suffering from language or speech problems. I even suspect that she might be disabled, and I wish she could get some medical help. My relationship with my grandchildren is good. The boy is good and seems to be doing well at school. Although his sister is also good, she does not talk a lot. I long to see my granddaughter. My daughter promised to bring her when she comes to see us, but I was disappointed when she did not bring her during school holidays when she came to see us".

"My grandson is getting tremendous support from his school and he is so eager to go to school. He gets both material as well as moral support. For example, he receives food parcels and his educator informed me that I should also inform other educators when he has to attend his treatment. The school is aware of my grandson's illness because I used to fetch him from school when he was attending his treatment".

"Our neighbours are not aware about the nature of my grand-son's illness. However,

his friends know that he is suffering from tuberculosis and do not seem to be bothered. I know that my grand-son is also receiving food parcels from the community centre”.

“My relationship with my daughters is good. When I have time I sometimes visit my daughter to help her with washing because she cannot cope raising those children alone”. “Yes, we don’t have any relationship problems”.

4.4 RESPONSES OBTAINED FROM EDUCATORS OF CAREGIVER ONE’S ORPHAN

The following questions (see Appendix Schedule 3) were posed to the educators of caregiver one’s boy orphan in order to ascertain some of the information given by the caregiver herself, which was relating to the welfare of the boy orphan at school:

- How did she come to know the orphan?
- Did you notice anything wrong with the boy orphan?
- What action did you take to help the boy orphan?
- Was there any learner support sourced from other educators?
- Are other learners aware of the HIV/AIDS status of the boy orphan?
- Is the orphan aware of his HIV/AIDS status?
- How is the orphan’s academic performance in class compared to the performance of other learners?

Like the other questions above, they were also not asked in any specific order, but depended on the responses given by the participant. The following responses were obtained from the educator:

“I knew this orphan when he was brought to the school by his aunt, after schools were re-opened. He was transferring from another school. His size was not compatible with his age and I asked his aunt if there was anything wrong with the boy. His aunt explained that the boy is HIV positive, and his mother had died of HIV/AIDS related disease.

"Furthermore, he does not get a social grant. I then decided to take the boy orphan to my class, as well as making arrangements with his aunt to take him to the community centre where he could receive food parcels." "These food parcels were supposed to be collected in the morning before the child comes to school, as well as in the afternoon when he goes home. I also requested you (referring to this researcher), as one of the members of the school based support team at the school, to make arrangements with the social workers, in order to restore the child grant for the orphan."

"It was easier for the orphan's educator to arrange all this since he was one of the school based support team members." "This researcher, being the other member of this team, as well as using the opportunity as a researcher with community and social justice advocacy orientation, was able to make sure that the restoration of the social grant by the Department of Social Development and Welfare was urgently attended to."

"Every case within the school has to be given to the school based support team for consideration and resolution."

"One of the educators also talked to the people responsible for the school feeding scheme to include this orphan in the list of those who receive food. I bought him shoes and my wife bought him a school bag."

"The school based support team also collected unused school uniform from some Grade one learners to give to this orphan since his size was similar to that of a Grade one learner. The school based support team requested help from some of the educators." "This help was in the form of unused clothes that could fit this orphan, and the support was excellent."

"It was the responsibility of the school based support team to monitor the condition and progress of any child who has been identified as a vulnerable."

"Although the child social grant was re-instated, I became worried about the orphan because he was no longer performing well in class even though he was the best performer in Grade five. I was also worried that his health seemed to be getting worse, and my suspicion was that he might not be attending his treatment at the clinic. I even

had doubts whether his aunt was fit to care for him or may be she needed some training. During my encounter with his aunt, I have a feeling that she may be having too much faith in the African herbs". As mentioned earlier, it has turned out during my interview with the aunt that the orphan was not collecting the food parcels from the community centre. His aunt informed me that she was not allowed to collect food parcels for the orphan. However, as mentioned during the interview with his aunt, I advised the caregiver to go with the orphan when he collected these food parcels.

"As this orphan's educators, we ensure that none of the other learners know about the HIV/AIDS status of the orphan, just to avoid discrimination against him from other learners. Thus, we do not know of any discrimination he might be suffering from other learners."

"We also do not tell the orphan about his HIV/AIDS status. However, we suspect that he may be aware about his status because one day when he was bleeding, he would not let his school mates to touch his blood". "

"At this stage it may be difficult to know exactly whether the orphan may be aware of his HIV/AIDS status since he has been informed that he is suffering from tuberculoses."

"It could be that he knows that no one should touch his blood from the teachings he received from school, as most learners are taught that because of different diseases, care must be taken in helping other people."

4.5 RESPONSES RECEIVED FROM MEMBERS OF A NON-GOVERNMENTAL ORGANIZATION WORKING WITH HIV/AIDS INFECTED AND AFFECTED PERSONS

Most of the caregivers complained about the lack of community support structures. However, where there were such structures, the caregivers complained about the inadequacy of support given by those structures. Therefore, this necessitated a need to identify one such structure and investigate the activities of the support structure. Members of one particular support group were asked the following questions (see Appendix Schedule 4), not in any particular format:

- What is the name of your organisation?

- When and how did it start?
- What are the core functions of the organisation, and how is the organisation structured?
- Is there any training you receive?
- What support do you give to the community?
- Can you highlight any special cases where you have assisted orphans or caregivers?
- What are your challenges?
- How can schools help to address some of these challenges?

The following responses from different members of the community organisation were obtained:

“The name of our organisation is ‘Dirang Ka Kagiso Community Organisation’. Women from different church denominations initiated this organisation. It was launched as an interdenominational organisation in November 2001. Initially, the organisation provided home-based care for the sick. We approached the Department of Health for assistance. However, the application was not successful even after they had requested us to provide them with our constitution and business plan. We then approached the Social Services Development Department, which was keen to help us. In 2004, the Social Services Development Department funded our project to the tune of R54, 000 for equipment. We were also given R200 stipend per person working in the project. However, they suggested that in order for us to continue getting funded, we also needed to focus on social issues, especially those affecting orphans”.

“We then decided to incorporate the social management department in addition to the health management department, which we already had. The health management department deals with the following issues:

- HIV and AIDS
- Nursing
- Social auxiliary

The social management department focuses on the following issues:

- Counselling
- Training of orphans and caregivers
- Identification of orphans, vulnerable children and caregivers
- Home visits
- Investigation of child abuse
- Application for birth certificates, identity documents, and child or foster grants.”

“Some of our members have or are receiving various training related to their field work. For example, those who are involved in health management receive training on HIV and AIDS, Nursing and social auxiliary. Those who are involved in social management receive training in basic counselling, welcoming of clients and home-based care. We are also receiving training on how caregivers are supposed to use the grant.”

“Regarding the health management, our trained staff ensures that sick clients are properly taken care of in terms of receiving medication for their illnesses. Our task is also to make sure that the sick are living in hygienic environment. For example, we sometime have to bath the sick and provide them with clean clothes.”

“Our social management department looks at issues such as identification of orphans, child-headed families and caregivers. We are working closely with social workers because when we have identified an orphan, and have identified a possible caregiver for this orphan, social workers have to complete the process of legal adoption. That is, social workers are involved in the assessment of caregivers. Sometimes we even help caregivers to obtain birth certificates for those orphans without them. This is done so as to hasten the process of applying for child or foster grants. While caregivers are waiting for foster grants, as it can be a lengthy process, we help them get child grants. The process of applying for foster grants is prolonged by the fact that there have to be some investigations regarding the suitability of the caregiver. After the grant has been approved, we make follow-ups to check and ensure that the money is used properly.”

"Child-headed families are assisted in retaining their homes after the death of their parents. Most of these children are removed from their homes by relatives who then take houses and make them theirs."

"We also investigate child abuses whether from the caregiver or community and report such cases to the police and social workers. This is where schools come in, since most of the educators could easily identify these abuses because they spend more time with learners. Our job is also to assist schools with counselling of these abused children since some schools are not properly trained to offer such services. We have been trained on how to approach the abusers, and this is crucial since if the approach is flawed, it could further endanger the life of the abused."

"Some of the activities we provide for orphans are social activities such as traditional music, poetry, dancing and drawing. We also meet them individually, to discuss their problems, as well as assisting them with their studies. We try to intervene where there is a problem between the caregiver and the orphan. Some of the genuine problems experienced by orphans include the caregiver not using the grant for the intended purpose, and food parcels given to orphans by community centres not benefiting the orphans."

"Although we do have programmes for caregivers, but they are not yet implemented. These programmes include briefing, team-building and personal development. Programmes such as these would also help caregivers be able to deal with issues such as stigmatisation, which is still a major problem in most communities. We have also realised that the community is not trained to identify caregivers."

"One of the benefits we provide for our clients is the funeral assistance. As most of our clients come from very poor communities, we normally approach the area councillor to assist us in convincing the local municipality to allocate freely, a place where to bury the dead. We also talk to one of the funeral parlours to offer free of cheap funeral services. We then contribute R1000, 00 for the whole funeral service. However, we do not expect families to cook any food for people coming to the funeral."

"Our biggest challenges are the following:

- education Department' unwillingness to cooperate with us – Some people within the Department of Education feel that we are interfering with the curriculum;
- educators are also alleging that we are interfering with the upbringing of children. For example, we had a client in one school and when we approach the school for help we would be referred to one educator who was not familiar with our organisation. This educator was being difficult to our member, and this resulted in the problem taking too long to be resolved;
- office space and children centre – We currently operating from someone's house. This makes it difficult since we do not even have a phone, which makes it difficult to address problems effectively and efficiently. Children do not have adequate space to engage in different activities. It becomes even difficult to discuss with orphans about their problems since we need private consulting rooms;
- funding – Due to insufficient funding, we always run out of funds, thus unable to continue with our programmes. We do not have transport to service our clients. When it is dry season, we cannot even have salaries for our workers. However, the Social Services Development still expects us to submit full reports. The department has advised us to look for sponsors, but it has been very difficult to get one;
- maintenance of satellite branches – We have satellite branches mostly in rural areas, which are quite a far distance from the main centre. Due to lack of transport and adequate funds, we are unable to reach our clients in those areas. For example, on one occasion we discovered that one of our clients in one of the rural areas had been dead for three months without being buried. The community in that area did not have a church, school or any means of transport. The community members used a dam or river for bathing, washing clothes, as well as drinking from the same dam or river. It was difficult to bury this client as no adult in that community was prepared to get involved. All the preparations were done with the help of the child who was related to the deceased. What made thing worse, was that the deceased did not have even a single document that could identify her;

- Identification of suitable caregivers – These problems emanate from family squabbles. Family members would fight to care for orphans because of child or foster grants;
- Resolution of abuse cases – Most people are reluctant to report child abuses such as improper uses of grants or even physical or psychological abuses. When such abuses have been reported to social workers or police, it takes too long to address the problems. Social workers and police complain of being understaffed; and
- Provision of birth certificates and ID – We still come across some administrative bottleneck when applying for birth certificates for orphans.”

“We would very much appreciate if schools could involve us in some of their activities. For example, schools could invite us to their School Governing Board (SGB) parent meetings. Perhaps we could be allocated some time just to inform the community about our work.”

“I would like to explain one case where one of the orphan was identified by one of our members. One of our members saw a boy passing her house, and she instantly became attracted to this boy. She asked the boy why he was walking on the streets without shoes when it was very hot. The boy said he just enjoyed walking even though he has shoe at home. The member bought this boy some bread to eat, but he decided to take it home to eat with his sister and cousins. Another day, the same member saw this boy walking with his aunt. She asked the aunt if they could discuss the boy’s situation. His aunt told our member that the boy was HIV positive, and his mother had died of HIV/AIDS related disease. After the member had explained the boy’ situation, we decided to put him on our programme, where he received food parcel while still waiting for the approval of the child grant. However, once he started receiving the grant, we stopped the food parcels. We also advised the aunt to apply for the disability grant for the boy.”

I gave details of the District Manager for one of the local Education Departments, so as to seek help whenever they experience problems with any of the district officials. I also advised them to request the School-Based Support Team of any school where they have clients to assist them.

CHAPTER FIVE

FINDINGS FROM THE EMPIRICAL RESEARCH

5.1 INTRODUCTION

The following sections will briefly state findings from literature, and these would be compared to findings from this study. The findings extracted from literature are explained below.

5.1.1 Findings from literature

The first problem experienced by caregivers of orphans is lack of knowledge regarding the formal adoption of these orphans (see Gerntholtz & Richter, on page 17 of chapter 2). Different categories of people eligible to adopt children are explained by Cape Gateway operating in the Western Cape Province.

The second problem for those who have knowledge regarding adoption face a lengthy process administered by an increasingly overstretched system (see Gerntholtz & Richter, on page 17 of chapter 2).

The third problem identified was bad behaviour by orphans (see second set of bullets on page 33 of chapter 2).

Fourthly, caregivers develop stress, which in many instances lead to their physical and mental health, personal relationships and standards of care suffering (see fourth bullet of first paragraph on page 34 of chapter 2 and Links and Masson, first paragraph on page 45 of chapter 2).

Poverty was the fifth problem identified in the literature review (see UNFP, 2007 on page 34 of chapter 2).

The sixth problem experienced by the caregivers was “role strain” and “identity” (see second paragraph on page 47 of chapter 2). For example, many grandmothers had

problems whether they should see themselves as mothers (as they are normally referred to by grand children) or grandmothers.

Interpersonal and family conflicts were identified as the seventh problem experienced by caregivers (see bullet 1 on page 49 of chapter 2).

Isolation and fear for the future was the eighth problem facing the caregivers (see bullet 2 on page 49 of chapter 2).

Excessive workload of having to care for children was the ninth problem (see bullet 3 on page 49 of chapter 2).

Stigma and discrimination relating to HIV/AIDS was the tenth problem experienced by caregivers (see bullet 4 on page 49 of chapter 2).

5.1.2 Findings from this study

This study was aimed at investigating problems experienced by caregivers of learners orphaned due to HIV/AIDS. On analysis of the findings, it has become apparent that there were general or common problems experienced by almost all the caregivers interviewed. However, in some instances, the study uncovered some problems that were specific to some caregivers. Problems identified in this study are discussed below.

5.1.2.1 Problem 1: Poverty

It is apparent from this study that most of the families interviewed could be defined as extended family systems. Only two cases were identified as foster care families, without any relations to the orphans. These caregivers can be classified as informal caregivers who are categorised as grandparents, aunts, uncles, siblings or even sympathetic members of the community (see Gerntholtz & Richter, paragraph two on page 17 of chapter 2). As in the literature review, poverty was identified as one of the problems facing caregivers in this study. Most of the caregivers were unemployed single-parent families, whose only source of income was the children grants received on behalf of their own children and their orphans. Another source of income was the foster grant received by the caregiver.

The findings in this study, suggest that although families are entitled to foster care and adoption grants, women entitled to state maintenance grants and AIDS patients entitled

to support as disabled people, not all who are eligible under these provisions are aware that they qualify for state support. Those who are aware are sometime limited by other requirements from collecting these grants, as in the case where the caregiver was unable to receive the foster grants due to orphans not having birth certificates.

The other problem, especially among the black South Africans, is that mostly women provide caring for persons with HIV/AIDS-related illnesses and orphans. As this study has shown, most of these women consider this type of caring as an obligation since most of these orphans are relatives. Therefore, they consider this as an unpaid work necessitated by a need to care for the loved ones. However, with the number of orphans expected to increase annually, this may increase the current level of exploitation by requiring more unpaid work. This may even contribute to existing gender inequality and exaggerates already high opportunistic costs for women. Furthermore, it may aggravate gender biases, with the possibility of contributing towards ongoing spread of HIV infection. This may result in caregivers' existing burdens limiting their ability to provide sufficient care for their orphans.

As this study has shown, the care giving families are distributed between female-headed households and the tradinional two-parent families, where more people are depended on fewer or no income earner. This lack of income is likely to put more pressure on AIDS orphans to contribute financially to the household (see Avert, 2007:2, chapter 2). In some cases this might even push them to the streets to work, beg or seek food, thus escaping the extended family safety net. Most caregivers received some form of grants. However, it is very clear that these grants are not adequate to alleviate poverty (see Table 2.4 on page 52 of chapter 2).

In this study, it has been made clear that long-term poverty has affected some households. For example, one child-headed caregiver noted that she was withdrawn from school because she could not afford school fees. She ended up getting involved in an abusive marriage for survival sake. It is well documented that female-headed households are among the poorest, and have little opportunity to escape from poverty.

5.1.2.2 Problem 2: Stress and depression

One or a combination of different kinds of behavioural problems displayed by orphans, which most caregivers complained about, included sadness; crying; withdrawal; aggression and attention seeking. Some of these behavioural problems displayed by orphans were the source of stress and depression in caregivers.

Most caregivers interviewed in this study fall under the traditional family safety net, where a large proportion of them are either aunts, uncles, grand-mothers or even sympathetic members of the community, who give fostering care to these orphans. In two cases, the orphans themselves were giving care to their siblings. Most of these caregivers complained about lack of proper training to deal with caring for such highly traumatised children. According to the transactional coping process as outlined by Figure 2.2 on page 41 of chapter 2, the environment makes constant demands on individual. This individual experiences these demands as stress (anxiety or tension) and has to decide how to manage the stress. The outcome of decision-making is either a coping response or reappraisal. For example, a child's withdrawal; aggression or attention seeking may become less stressing or depressing to his or her caregiver when the caregiver acquires knowledge that empower them understand the chronic stressors in the lives of traumatised children.

It has become apparent in this study that certain coping responses (orphan) have influenced the child's environment (caregiver). This in turn presented new demands on the individual or alleviated the stress. The following example based on one of the experiences by one caregiver interviewed, illustrates the reciprocity in the transactional coping process. An orphaned girl might have decided to cope with trauma by having sexual relationship with multiple partners, or be aggressive to other children. However, this choice increases her susceptibility to infection, yet provides her with money and recognition. Her stigmatised or depressed caregiver, avoiding discrimination or social rejection by the community, decided to send her to a school for the delinquent. If she becomes pregnant, or infected, or both, or her aggression leading to an offence, she may be expelled from school. This may in turn add her personal trauma to the distress already experienced by the caregiver.

5.1.2.3 Problem 3: Family fights

Another problem evident in this study was that of family squabbles relating to the care of orphans. The one problem that was uncovered was that of families fighting for the control of the child grant. The other problem was that of two families fighting for the adoption of the orphans based on family tradition and societal culture. In this instance the family home of the orphans was nearly auctioned and some assts distributed among relatives. These types of problems were also highlighted during the interview with one of the community support organisations. They cited these as some of the reasons that cause problems during the process of appointment of a suitable caregiver. Most of the caregivers interviewed were coming from disadvantaged and impoverished areas. Care giving for most of these people offers a possible means of income, as most are unemployed.

5.1.2.4 Problem 4: Adoption

The question of adoption is still not clearly understood by many South Africans, as reflected in this study. In one instance, the caregivers were denied an opportunity of legally adopting the orphans simply because the couple were not legally married.

According to this definition, it therefore suggests that one of the caregivers who were denied the opportunity of legally adopting their orphans, simply because they were not legally married are in fact, entitled to adopt them. These caregivers can be classified as “partners in a life-partnership”.

5.1.2.5 Problem 5: Bad influence of orphans by neighbours

Some caregivers reported bad influence of neighbour on their orphans. For example, one caregiver's neighbours concocted lies about the caregiver. These neighbours influenced one of her orphans to lie to the police that she has physical abused one of her orphans. This led to the caregiver being imprisoned for something that she had not done. This clearly shows how members of the community may exploit vulnerable children. Children orphaned by HIV/AIDS are often stigmatised by society. This feeling of shame, fear and rejection often leads to exploitation of orphans by the society, where orphans, due to wanting to be accepted by members of the society, would do anything demanded of them. Orphan and their caregivers are often not aware of their rights and

the laws intended to protect them from discrimination. However, even if they are aware they fail to demand better treatment from community.

If the care giving families are suffering from stress or depression, these orphans may escape the family safety net. They may end-up into the streets, thus becoming street kids, or being exploited as child labourers. Caregivers in trying to avoid having their orphans being badly influenced by the neighbours may ban their orphans from having any interaction with those they consider bad elements. However, according to social constructivism theory, language is developed through interaction of children with their parents or caregivers, siblings and the society at large, thus depriving children an opportunity to interact this way may lead to deprivation from learning and development (see Laurillard, paragraph 2 on page 33, chapter 2).

Laurillard maintains that children may be deprived an opportunity to interact with different sectors of the community through natural as well as deliberate action by the society. Deliberate actions or man made causes in this instance, could be abuse by the caregiver by refusing her orphans to interact with other children or neighbours. In Vygotsky's theory, the development of language and articulation of ideas was central to learning and development (see paragraph 2 on page 33, chapter 2). According to social constructivism, the learner being a member of a particular culture inherits historical developments and symbol systems, such as language; logic; and mathematical systems, and these are learned throughout the learner's life. It also stresses the importance of the nature of the learner's social interaction with knowledgeable members of the society, without which it is impossible to acquire social meaning of important symbol systems and learn how to utilise them (see, paragraph 2 on page 33, chapter 2).

5.1.2.6 Problem 6: Education

It is evident in this study that orphan children are being kept in school. In fact, caregivers are going to great lengths to keep their children in schools, and schools are being flexible in understanding the circumstances facing caregivers and their orphans. However, this study has also shown that children orphaned by HIV/AIDS may miss out on school enrolment, or have their studies interrupted, or even perform poorly in school as a result of their stressful situation. An example is a child-headed family caregiver whose schooling was interrupted after the death of her parents. Another example is that of an orphan who missed classes when his caregiver was collecting the foster grant, so

as to ensure that the caregiver buys him whatever he wanted. However, there were also aspects such as school fees, school uniform, transport and food, which presented major barriers because many caregivers could not afford these costs.

Schools are critical vehicles to help reduce the spread of HIV/AIDS (see paragraph 2 of chapter 1, page 3).

Ecological systems theory looks at the child's development within the context of the system of relationships that form his or her environment (see paragraph 2 of chapter 1, page 3).

5.1.2.7 Problem 7: Lack of training

This study has highlighted some deficiencies relating to the training of caregivers, in order to prepare them for the caring of orphans. Normal parenting is regarded as one of the most difficult jobs facing parents, especially women. Caring for orphans, especially those who have been orphaned due to HIV/AIDS, makes it even more difficult since most of them are traumatised by their losses. In fact, the importance of equipping caregivers with training was highlighted in the findings from one study, which suggested that caregivers should be able to access counselling and training on caring for children, children's rights and preparing a memory book (Exchange, 2004). The study purports that families and communities are the first line of response to the impact of HIV/AIDS on very young children. However, often communities in developing countries are seen as strong enough to endure any obstacle. But in broad-scale situations of poverty, coping mechanisms are strained to breaking point and traditional safety nets unravelling.

This inadequate training given to caregivers was also highlighted during interview with one of the community support organisations. It was indicated that although such programmes existed, the implementation of the programmes was their biggest problem. According to (Paquette and Ryan, 2001), communities must provide parents with access to people with similar concerns that can function as resources and emotional support. In fact, community support is a cornerstone of a "Family-Centred Approach" theory, whose key components are the following (Connard & Novick, 2001):

- Creating partnerships and helping relationships: families are supported and child development is enhanced through helping and partnership relationships;
- Building the community environment: families gain information, resources and support through their connections to the community environment;
- Linking families and community support: participation, two-way communication, and advocacy strengthen both the community support network and family functioning.

5.1.2.8 Problem 8: Lack of social support services

Some of the frustrations highlighted by caregivers were regarding the delays in issuing of birth certificates by the Home Affairs department. Caregivers complained of being sent from one department to another. For example, when orphans do not have proper documents for caregivers to apply for birth certificates, they would be referred to the social workers. However, social workers in turn would complain about their workloads and understaffing. This has even led to one of the caregivers abandoning any hopes of obtaining birth certificates for two of her orphans.

5.1.2.9 Problem 9: Lack of community support structures

Lack of community support structures surfaced from most of the interviews conducted in this study. Caregivers complained either of the absence of these structures from their communities, or their poor service. However, an interview conducted with one of the community support organisations highlighted some of the deficiencies experienced by such organisations. Problems experienced by the organisation included lack or insufficient funding, transportation costs, uncooperative government departments and some schools. Shortages of funds were their major problem since it contributed to failure of implementing certain community programmes.

It was evident in this study that this community organisation's programmes were mainly stifled by lack of funding. It is also possible that the organisation might not have been aware of other sources of funding at their disposal. It was also clear from the findings that most caregivers considered nongovernmental organisations as the only structures that could offer support. Other community structures such as small community

groupings of caregivers meeting to discuss and empower other members. Caregivers could also form faith-based organisations in their respective churches.

5.1.2.10 Lack of prior planning by orphans' parents

The Minister of Social Development, in the same conference on orphans and other children made vulnerable by HIV and AIDS, urged delegates to discuss one of the most critical but difficult issues, which was succession planning (SARPN, 2007). The Minister indicated that experience has deemed it necessary that in mitigating the impact of the epidemic on children, people need to proactively look at the issue of succession planning. He argued that families needed to confront this issue, and be assisted with the drawing up of wills and other important documentations and planning. The Minister asserts that such action will provide them with opportunity of choosing who will take care of their children, and what will happen to family assets such as the family home. Failure of parents in drawing up a will has led to fierce fighting between the paternal and maternal relatives of one of the orphans whose caregiver was interviewed in this study. The fighting was over the legal adoption of the orphans.

In fact, Levine reports that when a parent dies of AIDS in USA, surviving children face an uncertain future about their custody arrangements and financial benefits (Levine, 1995 cited in Ntozi, 1997). This kind of situation is also common in sub-Saharan Africa including South Africa. However, in most African countries paternal grandparents usually decide who should take care of the orphan. In a survey conducted in some regions in Uganda, households were probed on the person who made the decision on who is to care for the orphans. The study showed that the clan members (29.8%) followed closely by the parents (26.8%) and the orphans themselves (25.4%) made decisions (Ntonzi, 1997:29). The study showed that grandparents also made 14.8% of the decision-making.

Although this study was not meant to determine who was responsible for making the decision on who is to care for the orphan, it is probable that the grandparents made most of the decisions, except in the cases where foster parents were determined by social workers. Most of the orphans were under the care of either their grandparents, or their aunts or uncles, who might have been requested by the grandparents to care for the orphans. In one case, members of the community influenced the decision on who

was to care for the orphan. For example, some educators of one of the orphans requested the orphan's aunt to give care to the orphan. This child was initially cared for by his grandparents.

5.2 RECOMMENDATIONS AND MOTIVATIONS

This section presents recommendations based on both the findings from literature review and empirical research proceedings. The motivations for these recommendations are also provided.

5.2.1 Adequate *training* for caregivers and monitoring of grants for orphans

5.2.1.1 Motivation

Most caregivers are tempted to use grants for reasons other than for the intended purposes. This resulted in orphans not getting proper medication, food and transport to school.

5.2.2 Intervention from researchers in convincing the government for a need to continue issuing grants even after eighteen years of age

5.2.2.1 Motivation

This research has shown that caregivers, especially child-headed families struggle to maintain life when these grants are stopped when children reach eighteen years of age, and are still attending school or university.

5.2.3 Special grants or loans for university studies

5.2.3.1 Motivation

The normal grants given to caregivers for orphans are not adequate to make savings for their education.

5.2.4 Extra government incentives for caregivers

5.2.4.1 Motivation

As long as HIV/AIDS exists, there would always be a need for caregivers. These caregivers also use their private income to supplement the grants given for orphans.

5.2.5 Empowerment of Social Welfare Department

5.2.5.1 Motivation

Care giving is stressful and thus caregivers require constant support. Orphans are generally causing problems for caregivers, due to their unacceptable behaviour, which might be caused by the community or even relatives.

5.2.6 Training and empowerment of School-Based Support Teams (SBST) in schools

5.2.6.1 Motivation

Most caregivers look up to schools for support whenever they encounter problems with the orphans. Educators are the first to discover when learners are experiencing problems, even problems emanating from home or community. Schools are also in a good position to even identify orphans.

5.2.7 Capacitate and empower non-governmental organisations (NGOs)

5.2.7.1 Motivation

Proper training should be given to these NGOs since they play a vital role in supporting both caregivers and orphans. They should be financially viable so as to execute some of the projects intended for orphans.

5.2.8 Synergy between schools, NGOs, social workers, nurses and police

5.2.8.1 Motivation

All these structures are centred on the child thus require strong collaboration among them.

5.3 LIMITATIONS OF THE STUDY

Limitations of the current study should be noted. This study cannot show with absolute certainty whether the problems identified are related to orphanhood in general, rather than orphanhood by HIV/AIDS. It may be necessary in future to have a comparison group of caregivers of orphans due to reasons other than HIV/AIDS. However, Cluver **and** Gardner (2006:8) argue that this could be methodologically challenging in the urban South Africa, since the cause of death is frequently hard to ascertain and many reported non-AIDS death are due to AIDS.

Other limitations included reliance on one population race. The study cannot ascertain whether these findings can be applicable to caregivers from other race groups such as white or coloured races. South Africa is a multicultural society with different norms and values. Thus, the way we react to certain stimuli might be influenced to a large extent by our customs and values.

Further limitations included reliance on one specific type of caregiving. The study did not explore other type such as orphanages, but concentrated on what is regarded as the traditional safety net.

5.4 CONCLUSIONS

This study investigated through literature review as well as empirical research, problems experienced by caregivers of orphans due to HIV/AIDS. There were similar problems revealed in this study to those identified in the literature. For example, both literature and this study revealed poverty, stress and interpersonal and family conflicts as major problems experienced by caregivers. Grandparents and other family members who were caregivers in this study did not see "role strain" and "identity" as major stumbling blocks. Stigma and isolation were also some of the problems not directly experienced by most caregivers. However, it was evident that some of these caregivers who did not experience stigmatisation and isolation was due to their less involvement with community members.

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APPENDIX SCHEDULE 1

INTERVIEW QUESTIONS FOR CAREGIVERS

1. How many orphans are under your care?
2. How did you know about the orphans, and why did you take them into your care?
3. What is the relationship between you and the orphan/s?
4. How long have you provided caregiving?
5. What type of parenting are you giving to this/these orphan/s (e.g. adoption or foster)?
6. Can you explain the type of family structure that exists in your home (e.g. single; traditional; child-headed or orphanage)?
7. How is the relationship between you and these orphans?
8. Do you have any other children except these orphans?
9. How is the relationship between these children and the orphan/s?
10. How is the relationship between your relatives and these orphans?
11. Are any of these orphans infected by HIV/AIDS?
12. Are they aware of their HIV/AIDS status?
13. Would you advise other people to be caregivers?
14. Can you give account of your own health status?
15. How often do you attend treatment for your illness?
16. Did this illness start before or after caring for your orphans?
17. How does carrying for children orphaned due to HIV/AIDS affect your approach to life?
18. Do you personally give treatment to orphans infected by HIV/AIDS?
19. Have you received any training or counselling regarding treatment of HIV/AIDS infected patients?
20. How many people are working in the family?
21. Is there any other source of income for the family?
22. Do you receive any social grant?
23. What are the basic needs of the orphans?
24. Is the grant sufficient for all these needs?
25. What else do you use the social grant for?
26. Are the orphans aware of the social grant you receive on their behalf?
27. If orphans are aware of the social grant, are they not demanding to have full control of the usage of this grant?

28. How is the relationship between you and your neighbours?
29. Does this relationship affect the orphans in your care?
30. Do orphans under your care have friends in the community?
31. Are the orphans in your care having a good relationship with the other community members?
32. Is the community aware of the HIV/AIDS status of orphans in your care?
33. What kind of support do you get from your community?
34. Are you aware of any support groups in your community?
35. Are any of your orphans attending school?
36. Do you get any support from the schools where they attend?

APPENDIX SCHEDULE 2**INTERVIEW QUESTIONS FOR OTHER FAMILY MEMBERS (GRANDPARENTS)**

- 37. Can you give me some background relating to the orphan's parents?
- 38. What was the cause of their mother's death?
- 39. Did she attend any support group meetings before she died?
- 40. Are any of your grandchildren having health problems?
- 41. Do you know what could be causing these illnesses?
- 42. Is the orphan aware of the cause of his illness?
- 43. Is he getting any treatment for his illness?
- 44. How is your relationship with the orphans?
- 45. How is your relationship with your neighbours?
- 46. How is your relationship with your children?
- 47. Do you get any support from the community?
- 48. How is your grandson performing at school?
- 49. Is there any support he gets at school?

APPENDIX SCHEDULE 3**INTERVIEW QUESTIONS FOR EDUCATORS**

50. How did she come to know the orphan?
51. Did you notice anything wrong with the boy orphan?
52. What action did you take to help the boy orphan?
53. Was there any learner support sourced from other educators?
54. Are other learners aware of the HIV/AIDS status of the boy orphan?
55. Is the orphan aware of his HIV/AIDS status?
56. How is the orphan's academic performance in class compared to the performance of other learners?

APPENDIX SCHEDULE 4**INTERVIEW QUESTIONS FOR NON-GOVERNMENTAL ORGANISATIONS (NGOs)**

57. What is the name of your organisation?
58. When and how did it start?
59. What are the core functions of the organisation, and how is the organisation structured?
60. Is there any training you receive?
61. What support do you give to the community?
62. Can you highlight any special cases where you have assisted orphans or caregivers?
63. What are your challenges?
64. How can schools help to address some of these challenges?

