

## **CHAPTER 5: FINDINGS, CONCLUSIONS AND RECOMMENDATIONS**

### **5.1. INTRODUCTION**

In the previous chapter the research design and methodology were discussed. This chapter presents the findings of the research as they emerged from the data collection and analysis. On the basis thereof conclusions will be drawn and recommendations will be made to address the psycho-educational needs of AIDS orphans. The research questions which were formulated in Chapter 1 paragraph 1.4. are presented again for consideration.

### **5.2. RESEARCH QUESTIONS**

The primary research question that the researcher wished to answer was:

- What are the psycho-educational needs of AIDS orphans as perceived by their caregivers in day care centres?

The following secondary research questions were formulated:

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

### **5.3. FINDINGS**

The findings emanating from the process of data analysis are subsequently presented. The primary research question is answered in paragraph 5.3.1. The first two secondary research questions follow in paragraph 5.3.2. and 5.3.3. The answer to the third secondary research question can be found under 5.6.: Recommendations.

#### **5.3.1. Findings with regard to the psycho-educational needs of AIDS orphans as perceived by their caregivers**

These findings are presented in the form of the psycho-educational needs as perceived by the caregivers of the AIDS orphans.

##### **5.3.1.1. The need to socialise and communicate**

Caregivers told many stories about problems that the AIDS orphans experience in their social lives. One problem frequently mentioned is their reluctance and/or inability to talk and communicate effectively. It seems as if AIDS orphans are unwilling to express themselves, and that they find it very difficult to open up to someone and share their problems.

In this regard, *Mama* (fictitious names are used for caregivers), with whom the very first interview was conducted, said:

*“It is very heartbreaking when they come here, because some of them are very, they are very quiet and they are very sorry for themselves, you can just see – sometimes they don’t want to talk, they don’t want to even mix with other children.”*

Another participant said:

*“There were like two – one brother and one sister here, they would go outside and play but they will just stand together, and look at others playing, and not even talk to each other, because they were very sad (...)”*

Because of the children’s reluctance to speak, their real needs are only revealed over a long period of time. This is one of the reasons why children who are able to sleep over at a day care centre appear to have an advantage over those who simply come for the day, or even only for a meal. Children who stay over at the day care centre receive immediate attention. Even if they do not speak, their caregivers keep an eye on them, trying to win their trust by small tokens of love, such as taking them for a shopping trip to town etc. More examples of the children’s reluctance to speak as related by their caregivers are as follows:

*“She says many times when she asks them, they don’t speak – they just keep quiet.”*

*“She says because they – starting to – I mean – they are not so small – too small anymore, so, it’s difficult for them to just – speak up and – be open about that. So she says here it’s very rare for her to maybe hear them speaking about that.”*

*“She also notices that sometimes if they cry and they ask them what is the problem? They don’t say. Like she said the other ones they’ve got the mother who’s sick now, they’ll come in here, and they’ll put their hands here, and do funny things, and they’ll ask them, why, and they will – they will just sit down and say nothing, so everything is fine, they don’t want to speak about it – you know.”*

*“She says there’s a big difference between these children (and normal children), because it’s difficult to work with the orphans, because you can’t speak easily about things – and you know*

*you just notice here and there that there might be something wrong and – you have to dig them before they can speak – and it needs much commitment, you know.”*

*“She says here this point of - withdrawing, and - not wanting to speak to anybody - difficulty, you know, to be open and speak about the problems - it happens for a short period when they come here, but after some time they are able to help them and they can open up and speak”.*

(The last quote stems from a caregiver at the care centre where children sleep over).

The last portion of the quote raises a point which will be mentioned again. The AIDS orphans' communication with the caregivers at the centre where they sleep over seems to be much better than at the care centre where they simply stay at the centre during the day. Atwine *et al.* (2005:556) agree to this consideration by maintaining that fluctuations in children's grieving behaviour are the order of the day, making it difficult for adults or caregivers to identify grieving behaviour on which to model appropriate responses. As a matter of fact, it seems that real and effective intervention (also with regard to communication) can only take place when the children actually live with the caregivers on a day-to-day basis and are taken out of the environment where they might experience abuse and other factors that impact negatively on their development. As a caregiver at the sleep-over facility revealed, children's silence and their unwillingness to communicate only lasts for a short period of time until the children see the confidence that their peers at the care centre have in living and they simply cannot remain untouched. Conversations with caregivers at the centre where children could not sleep over made it clear, however, that those caregivers found it very difficult to reach a point where the children were willing to speak about their problems or the difficulties they experience, in spite of the fact that the caregivers could see that something is wrong in a child's life. The fact that the AIDS orphans are so reluctant to speak is a stumbling block for their development. Li, Naar-King, Barnett, Stanton, Fang and Thurston (2008:147-148) state that their cross-cultural research on the grieving process revealed that people of all cultures need to acknowledge their grief and talk about it in order to work through their loss.

There appears to be a cultural factor which contributes to the AIDS orphans' reluctance to speak. When the researcher asked one of the participants why the children struggle to talk or whether they are ashamed to be an orphan, she received the following answer:

*“The problem sometimes is that, I mean as Zulu people, if you are young – many times you are very scared to be open up with our problems to the elders, you prefer to even go and speak to your friends, and things like that, but not, you know, older people”(...)*

Reluctance to speak to a caregiver about personal problems seems to constitute one of the AIDS orphans’ difficulties in communicating. One should however, be careful to generalise this observation to other children from the Zulu culture. It is also very probable that orphaned children in a variety of cultures may struggle with this aspect of communicating. A strategy which the caregivers could use to find out what is wrong with a child or what he/she is struggling with, is to observe which children are close to a particular child. A participant said that she would then approach the particular child’s friend in order to get to the root of the child’s problem and thus be able to provide effective help. Communicating with the children and building a relationship of trust really appears to be one of the biggest challenges that caregivers face.

One huge problem related to communication seems to be that the AIDS orphans frequently complain about being ‘ill’, thereby internalising their problems rather than speaking about them and dealing with them constructively. Reference to somatic complaints of orphans can be found in the literature (Doku, 2010:26). Kiggundu and Oldewage-Theron (2009:390) found that guardians and caregivers of AIDS orphans often suffer from stress-related illnesses as well. In spite of the fact that the frequent manifestations of ‘illness’ among orphans may be linked to their inability to disclose their feelings and the subsequent internalising of problems, one should still keep in mind that stress-related illnesses are also a possibility and may be serious in nature, given enough time to develop.

A caregiver said the following about how she assists orphans who pretend to be ‘ill’:

*“Some of them, that’s actually a big problem – when they start - try to look for excuses so that the Aunty does not see that there’s something wrong with them. Or if they have a problem, like excuses, they become very sick very often, then but actually when she sits down with them and asks what is the problem, then they will start opening up like, for example one of the children who said to her, she still remembers because her mother passed away in front of them – what was her last reaction, and all that, and then she will just speak about, and afterwards, they come right, they play around with the children, ja.”*

The findings revealed that the orphans need a great deal of assistance in learning to communicate and socialise. Communication is necessary for them in order to work through their problems. What makes matters worse is the fact that AIDS orphans may be reluctant to reveal their orphan status, since their society and culture considers this to be a disgrace. Chakalane-Mpeli and Roets (2007:83) refer to social isolation as one of the factors accompanying the diagnosis of HIV/AIDS. In order for AIDS orphans to accept themselves, they must understand who they are, and that others and God have accepted them as they are. Being accepted and loved can free these inhibited children to speak, to share their problems and be helped, since their culture encourages silence on the matter and emotions and great needs are thereby suppressed. One of the younger caregivers, who is an orphan herself, also stated that one of the main aims of care giving when a child comes to the centre, should be to assist the child to accept his/her situation as it is.

It was mentioned before that AIDS orphans as a rule do not easily speak to older people about their problems and how caregivers may even approach children's friends in order to find out what is wrong with them. The children at the care centres, more particularly, at the care centre where some of them stay on a full time basis, seem to be very sensitive with regards to the type of relationship that their peers develop with caregivers. One of the caregivers made it clear that they do their best to approach all children equally, and not to single out any children. The caregiver related, however, that some children themselves may attempt to establish a closer relationship with one of the caregivers. Another caregiver confirmed this, stating that a situation between two children may have developed and because the one child has observed the other one's close relationship with one of the caregivers, he or she may be reluctant to come and speak to that caregiver (who is perceived as being 'close' to the other child) about the matter. This kind of sensitivity to a 'close relationship' with the caregivers, may be illustrative of AIDS orphans' need for close relationships.

Thupayagale-Tshweneagae and Benedict (2011) wrote an article titled "*The burden of secrecy among South African adolescents orphaned by HIV and AIDS*". They describe that "*HIV thrives in an atmosphere of silence and secrecy*" (Thupayagale-Tshweneagae & Benedict, 2011:355). Thupayagale-Tshweneagae and Benedict (2011:355) warn that the stigma accompanying HIV/AIDS makes access to much-needed help difficult for AIDS orphaned adolescents. Thupayagale-Tshweneagae and Benedict (2011:355) also mention that grandmothers raising orphans may contribute to their communication problems. The literature likewise confirms that orphanhood and the stigma accompanying HIV/AIDS may lead orphans to isolate themselves from their peers, as has been discussed previously (Chakalane-Mpeli & Roets, 2007:83). In his

article on the “*psychosocial adjustment of children affected by HIV/AIDS in Ghana*”, Doku (2010:25) identifies withdrawal, antisocial behaviour and depression as symptoms of stress and trauma that AIDS orphans display.

In the light of the findings and supportive evidence from literature, it becomes clear that AIDS orphans are clearly predisposed to socialisation problems, especially since the stable emotional attachment with a parent, and more particularly a mother, is wanting.

#### **5.3.1.2. Need for coping with parental death**

Chakalane-Mpeli and Roets (2007:82) state that “*terminal illness or death of a parent due to HIV/AIDS has a disastrous effect on the surviving children*”. The grieving process of AIDS orphans is expected to be particularly complicated, since “*grief may precede the actual death in the form of ‘anticipatory loss’*” (Wood *et al.*, 2006:1924). Sandler, Ma, Tein, Ayers, Wolchik, Kennedy and Millsap (2010:131) refer to the shock that the child experiences at the time of death of a parent which may result in a range of problems relating to their mental health, beginning in childhood and even persisting through adulthood. Li *et al.* (2008:148) also state that “*children in particular are at an increased risk for unresolved or complicated bereavement because of their developmental vulnerability (e.g. intellectual immaturity and emotional dependency)*”.

Children of different ages experience death in diverse ways and display varying degrees of understanding of the concept of death. Only when children reach the age of ten years, can they understand that death is irreversible (when a person has died, his physical body will never return to life) and that dead people are non-functional, meaning they are unable to do the things a living person can do (Rosner *et al.*, 2010:102). Thus, the deduction could be made that the death of a person or close relative may have more lasting effects on an older child since that child can better comprehend the finality of what has happened. The fact that young children do not always grasp the finality of death may also, however, complicate their grieving process, as they may still cling to the unrealistic expectation that their parents will return. The quote which follows indicates that younger children may become confused as to what has happened to their parents and become irritated by their own lack of understanding of their parent’s death.

One of the caretakers said that “*some of the children will go to the grave every time, and just sit there and think, maybe - her mother will come back*”. A cultural factor which complicates matters is the custom of not telling children what the cause of their parents’ death was. The aspect of secrecy surrounding HIV/AIDS is confirmed in literature on the subject (Wood *et al.*,

2006:1924). The secrecy or silence inhibits the child to speak openly about his/her feelings about the death of a parent. Thupayagale-Tshweneagae and Benedict (2011:355) mention that when a child realises his/her parents have died from HIV/AIDS, a vast number of questions such as the following arise: *“How did he or she acquire the disease? Do you have it? Can I get it from you?”* In this regard Mama mentioned that *“some of them will come to her and they will tell her that they still remember their parents and they are just wondering, why did they die and what was the cause of their death? And she will speak to them and tell them that they might accept it (...) most of them don’t know what was the cause of their parents’ death (...) because the members of the family or the relatives don’t tell them what was the problem, was the cause of their parents’ death”*.

The possibility also exists that children start drawing their own inferences as to why their parents died. One of the younger caretakers related that *“one of the children said to her, her mother was very sick, she got very thin, you see – at school they are taught about HIV and AIDS, and then she said, maybe she died of AIDS, you know. She was just thinking on her own, but nobody told her. Because she knew her mother lived an immoral life before.”*

Since relatives do not inform children about the causes of their parents’ death, AIDS orphans struggle with the problem of finding someone whom they can trust, seeing that they cannot speak to those who are naturally close to them. They face the additional hurdle of having to first develop trust in a ‘stranger’ before being able to work through their grief. These aspects are real day-to-day stress factors AIDS orphans have to deal with, a daunting prospect at such a young age. It is not difficult to imagine, therefore, what a great deal of emotional support these children need if they are at the same time required to manage school work and other aspects of their day-to-day lives.

The following extracts from an interview with one of the caregivers illustrate the effect that a mother’s death had on a particular child:

**Mama:** *One of the girls would look at the pictures of her mother, and then she will get sick, like get a headache or something like that, but then afterwards, when they spoke to her, and then she opened up, because one of the children noticed that she was always looking at these pictures, and they will just - they will just see, I mean, the change, you know, in her face and everything...*

**Researcher:** *After one of the other children spoke to her?*

*Mama: No, after they had noticed that she was looking at those pictures, so they were able to see that there was something going wrong with her, and then - in that way they helped the Aunty as well.*

AIDS orphans become despondent because of their parental loss. One of the caregivers who is very closely involved with the children said that *“when the children come here, they have this thing on their minds that they don’t have parents anymore, it’s like they have nothing left, and there is nothing that will be coming in future for them”*. However young the children may be, they feel that their parents’ death has taken away their source of care and comfort and hope for the future. They become preoccupied with a problem that they were not meant to be confronted with at this potentially care-free stage of life. They are worried about their personal survival and the future. Therefore one can understand why these orphans become despondent, cry, lose their joy in living and see no point in playing with, or talking to others. To compensate for their feelings of despondency, one of the caregivers wished they could have more resources like toys or other activities that they could give to these children to distract them from the worrying thoughts that seem to preoccupy them.

Literature also points out that orphans’ aggressive behaviour and their tendency to become moody, undisciplined and unruly is related to their grief. In Kiggundu and Oldewage-Theron’s study (2009:392), a grandmother related: *“My grandchildren have got a temper. I am sure they have not come to terms with the death of their mother and they are looking for someone to blame”*. The problem of discipline was also mentioned by the caregivers in the present study and seemed to be related to the fact that the AIDS orphans often do not want to accept authority and disciplining from somebody other than their mother. The caregivers also suggested that the orphans struggle to come to terms with the fact that their parents are not there, and somebody else is going to take care of them now. A caregiver recounted: *“Most of the children just cry easily, even if you try to help them, they’ll be – ‘because you’re not my mother, that’s why you doing this to me’”*. This self-same caregiver likewise stated that the children were short-tempered, concurring with evidence from Kiggundu and Oldewage-Theron’s study (2009).

### **5.3.1.3. Need for acceptance**

It became clear through the interviews that the children generally dislike to be called orphans. It causes them to feel excluded, and they are teased at school because of their orphan status, as one of the previous quotes revealed. This quote is repeated once again, in order to emphasise the children’s experiences when they are referred to as ‘orphans’.

*“There is a Zulu word, intandane, which means, an orphan - they don’t like to hear people calling them orphans and -, because it actually reminds them of what happened to them, and they feel excluded, you know, from normal children who have both parents.”*

One of the younger caretakers mentioned that the children are teased at school because of their orphan status:

*‘Ja, they do get things like that, especially at school, because they don’t even like to be called by ‘orphans’, you know. It is not a nice word for them.’*

The stigma attached to HIV/AIDS is well-documented and confirmed by the literature (Ogunmefun *et al.*, 2011; Chao, Gow, Akintola & Pauly, 2010; Chan, Rungpueng & Reidpath, 2009). Children whose parents have HIV/AIDS are more stigmatized than children whose parents suffer from other medical conditions (Li, Barnett, Fang, Lin, Zhao, Zhao, Hong, Zhang, Naar-King & Stanton, 2009:732). Added to the stigma of HIV/AIDS, is the fairly common occurrence of child abuse by family members who care for these orphans. The things that are done to these children by their closest relatives, such as sexual abuse (Cluver & Gardner, 2007a:321) are horrifying and most certainly add to the distress these children already experience. Abuse will be further discussed under another section and it is something that adds to the pain and exclusion AIDS orphans already experience. One of the caregivers related that one of the orphans said that *“...even in the area people did not like her at all”*. AIDS orphans display a great need for acceptance, as they frequently feel excluded. Their families often add to their misery by making them feel unwelcome.

#### **5.3.1.4. Need for security and care**

There are a number of aspects that emerged during the interviews which can be grouped under the umbrella term “need for security and care”. According to Chakalane-Mpeli and Roets (2007:83) AIDS orphans often experience abandonment and a lack of shelter. Abuse by family members is an aspect that was already mentioned in the previous paragraph and this also contributes to AIDS orphans’ need for love and security (Nyambedha *et al.*, 2003; Chakalane-Mpeli & Roets, 2007:83). They are deprived of a safe home environment where they are loved and being taken care of.

In the face of the additional financial burden which AIDS orphans cause to the extended family, they are frequently not properly cared for. To some extent, this is understandable, seeing that the

millions of AIDS orphans cause “*higher dependency burdens*” to households (Kuo & Operario, 2010:1; see also Abebe & Aase, 2007:2060). Relatives are not necessarily pleased with the prospect of having to care for the AIDS orphans and it may happen that the orphans have to go without food or are subject to other disadvantages in favour of parents’ own biological children.

There are two main theories on caring for the large number of orphans in Africa. The first is based on the so-called “social rupture thesis” and implies that the extended family system has reached its limitations within the context of the rising amount of orphans (Hutchinson, 2011:19; Abebe & Aase, 2007:2058). The aforementioned references to abuse may be related to this theory. The social rupture thesis also seems to rest in the perception, that children are particularly vulnerable and stresses the fact, that in losing their parents, they have lost an essentially safe, secure and care giving environment (Hutchinson, 2011:19). The second theory is rooted in the idea that, given appropriate support, the traditional extended family system can still absorb large numbers of orphans (Abebe & Aase, 2007:2058). This latter perspective emerged in view of the observation that certain societies confronted with a major HIV/AIDS epidemic were managing the crisis better than had been expected (Hutchinson, 2011:20). The foundation for this was found in factors such as resiliency, coping mechanisms, and strategies that adults and children have developed in response to hardship caused by HIV/AIDS (Hutchinson, 2011:20).

I would like to support the notion that relatives can play a supportive role in the lives of orphans, provided that healthy relationships exist, and that relatives and orphans support each other towards survival strategies and resilience. However, the stories related by the caregivers in this study seem to point at the necessity of removing AIDS orphans from abusive conditions, as it becomes difficult to develop resilience under the circumstances that they face.

The present study portrayed a bleak picture with regard to the security and care of AIDS orphans within the extended family system. Naturally, this portrayal may result from the fact that the orphans at the care centres have been identified as those most in need, and are subsequently more likely to present a family history of abuse and neglect. While the ‘resiliency perspective’ is more orientated towards an internal locus of control in which children are seen as capable to take charge of their situations, the sad evidence emerging from the study indicates that if children have not developed much-needed resiliency and coping strategies, they will often fall prey to factors such as stigma, abuse and discrimination. This clearly shows that the vulnerability of these children should never be underestimated, and that they need assistance in fighting for survival. In view of the evidence of developmental difficulties and problems which AIDS

orphans display, the importance of a secure family environment for the healthy development of children is emphasised (Berger, 2003; Berk, 2004; Goldfinch, 2009). The following extract from the interviews with the caregivers illustrates the hardship and neglect that some of the orphans endure:

*“And one of the children had to stay with her sister – who was married, and then they said as the family of her husband, and then this child got very abused, because the – her sister’s mother in law said – she must not eat – the children of the house must eat first – and then she must come last – so every time she will think about that, and that really abused her so much, and that she was so thankful to come here, because she was free to eat whenever she wants, and openly. And then – (Translator inquires) – sorry it’s a boy, and then he ended up – doing robbery at the houses to get food because there was – they were not giving him enough food to eat.”*

Cluver and Gardner (2007a:321) confirm this kind of neglect which they term “*unequal distribution of resources*”. Participants in their study were very aware of problems with regards to discrimination against orphans in comparison to parents’ own biological children (Cluver & Gardner, 2007a:321). A child reported in Cluver and Gardner (2007a:321) about how s/he feels about staying with a foster family: “*When you’re living with another family and they buy clothes for their children and not you*”. Personally, I think, this is one of the most painful experiences of rejection and lack of care a child can experience – being discriminated against in such a way by those that are closest to him/her. Incidences of abuse and deliberate neglect of orphans within the extended family system are tragic, given the fact that kinship support in crisis times actually has the potential to meaningfully contribute to children’s social and psychological health. This may be due to the blood and relational closeness of family members (Abebe & Aase, 2007:2060).

The following is an example of deliberate lack of communication which caused a great deal of distress to a child as narrated by one of the younger caregivers.

**Caregiver:** *There was one child who is here who had a problem, you know if you are, if you are born out of wedlock, and then her mother dumped her by the hotel, and then somebody find her, and then they used that surname for, for – it’s a girl? (translator inquires) Yes – for her, so now she, after, while she was growing up she inquired that – is this my real surname?, because she finally find out that she did not belong to that family, but then they refused to tell her exactly what happened.*

**Researcher:** *So they actually adopted her? Somebody else found her?*

**Caregiver:** *They did not adopt her officially, they just took her in. So now, while she was inquiring about that, the – I can call it adoptive parents – something like that – refused to take her to her mother’s place because she knew her mother personally, who dumped the baby. So now she was so confused because – that person was able to take care – at least just tell her – what her real surname is – so that she would not get confused – but then they refused to tell her – they said, it’s just enough for her to know that her mother dumped her and she is now using this surname. So that really made her – confused her, she even has a scar somewhere here, because they used to beat her when she was inquiring about the surname.*

**Researcher:** *What needs does a girl like that have after she’s gone through – what are the problems she experiences, or that she experienced when she came here? What did she struggle with?*

**Caregiver:** *She says she used to speak about it and just cry and say, she does not know her real surname and that – you could see that she was really abused, and she would even say that even in the area the people did not like her at all.*

This account once again illustrates how the AIDS orphans is stigmatised by the community. Added to the family abuse, there was evidence that the people in the area where the orphan lived, disliked her, which increased her personal misery. The families where AIDS orphans are supposed to be cared for, become the very places of insecurity. This account also indicates that AIDS orphans may develop problems with regard to their personal identity. Since they need to cope with abuse and issues of rejection, finding their personal identity may become very problematic. This problem becomes more complicated when children do not receive any information about their biological roots. The result may be identity confusion, because one of the main tasks of adolescence is to establish a personal identity (Berger, 2003:39).

The younger caregiver who related these aspects, shared her own story which is very similar. She was given away by her mother who was 15 years old at the time of her birth to another woman who could not have children. She then grew up with this other family, only to find out one day that her real mother had passed away. She then realised that she actually had a different surname, about which she inquired. However, she desired to keep her adopted surname seeing that the other woman who raised her had treated her as a child. When her second, ‘adoptive’ mother also passed away, she faced complete rejection by the family in which she had grown up. They

simply told her to leave, because according to them the only reason why they had tolerated her, was for the sake of the late mother who could not have children. In this tragic way, the girl's childhood environment in which she experienced security, crumbled when both her mothers passed away and she was left to the mercy of a family who abused her in a way she never expected. It seems as if abusive situations such as these are common occurrences in the lives of AIDS orphans. They are being maltreated for no good reason, and they struggle with suppressed hurt and anger against these abusive family members. The girl whose mother gave her away states that she *“even thought of paying revenge to her mother if she was still alive”*. In another case, the following was told by a caretaker: *“And the other thing is that – one of the girls confessed or spoke that – she was very angry at her grandmother because she abused her. But then, now, she – started to forgive her, and everything is like – going well, and she experiences the Lord helping her, to get over that.”* The caregivers with whom the interviews were conducted emphasised that children need to be assisted in accepting their present situations and also to forgive the people who hurt and harmed them in some of the ways described previously. Finally, it seems as if Zulu people do not talk about abuse that has taken place within the family situation. This makes it difficult to trace the person(s) who abuse AIDS orphans. In this regard, Mama gave the following account:

*“There are quite – stories about that – the first one is that have been abused – sexually, like raped, but then – Zulus are quite different from white people. They wouldn't like – come out and be against that family member who does that to a child. You will get that the child will report about the problem, but maybe one of the family members, even the mother of the person who's raped the child, will say, no, no, no, I don't know nothing about that – don't start speaking about that – because that is not true, you know – and then but what they will do is that they will just stop running after the families and things like that, and try to help the children, because it's here already – they can make an influence, you know – to change his or her life.”*

It seems as if caregivers at the care centres have also given up to find family members who have abused children and instead attempt to give all the support they can to abused children at the care centres where they try to create an environment of care and security.

#### **5.3.1.5. Need for love and belonging**

It has been mentioned before that the orphans at the care centres tend to feel less loved if one of their peers develops a relationship with a caregiver, which seems to be closer than their own relationship with that caregiver. This observation indicates that there is a considerable need

among the AIDS orphans for developing an intimate relationship with a care giving person. Experiencing such a relationship gives children the feeling that they are special and loved while at the same time providing them with an open door for talking to somebody when they experience difficulties or problems. The loss of a biological parent instils this strong desire in orphans to establish another strong emotional bond with a surrogate parent.

The narrations of the caregivers indicate that AIDS orphans have a strong need for love and attention, a need to belong somewhere, to be treated as human beings and to establish their own personal identities. Orphans' strong need to belong has been noted in literature. Cluver and Gardner (2007a:321) refer to orphans' descriptions of abandonment and the need for 'belonging' to a family.

At the care centre where orphans sleep over, caregivers attempt to create a structured family unit and they are open to the children about their reasons for doing things in a certain way. This structure and discipline puts the children at ease and causes them to feel that they are cared for by fair and reasonable adults. At the day care centre where the AIDS orphans cannot sleep over, communication and discipline are more problematic. There, the caregivers complained that the orphans tend to reject disciplinary measures in the light of the fact that the caregivers are not their real parents. There the caregivers also often struggle to find out what is troubling the children and the children find it difficult to understand the good intentions and love of the caregivers' actions (the caregivers are elderly grandmothers from the community). In general, the children are very sensitive when being reprimanded and will say that "*because you are not my mother, that's why you are doing this to me*". This quote shows how AIDS orphans display a lack of basic trust in people which somehow comes naturally to children who grow up in healthy homes, believing that the world they are living in is a good place to be. AIDS orphans seem to be rather distrustful towards their environment, and for this reason, caregivers often have to go to great lengths to win the children's trust.

The extent to which the AIDS orphans are in need of love and affection can be seen in the following excerpt:

***Mama:** She says the main point for her, and that she would like to emphasise that - showing love to the children is actually more - important than any other thing that you can do to the children. Because it's, it's like - is that personal relationship between the caregiver and the child and - the child can see the love and care from the caregiver.*

**Researcher:** *Why is it so - why does she think do they need so much - why is that - why is that their biggest need?*

**Mama:** *It's because she's seen the results, you know, of - showing love to the children because, after some time, they, they will see them opening up - like, being free and able to speak to one another, and have a good relationship, ja, with each other.*

(...)

**Researcher:** *What did she herself learn through her experiences over the years with the children?*

**Mama:** *Shame, she says she is sorry to keep on repeating one and the same thing but -*

**Researcher:** *- but that's good! (Laughing)*

**Mama:** *It's just - eh - love, and welcoming them that - she's learnt is very important with the children. And she says - she really loves the children - all of them, they are really - like in her heart and she likes taking care of them.*

The need for love and affection is not unique to the orphans of this study. Orphans participating in Mangoma's, Chimbari's and Dhlomo's study (2008:124) reported that they "*lacked parental love and were often frustrated, and hence they felt empty and lonely with no-one to listen or talk to like they used to do with their parents*". It seems that abusive experiences in particular create a great need for love in HIV/AIDS' orphans' lives. Amongst others, Mangoma *et al.* (2008:126) name group stress, frustration, and a lack of parental love to be AIDS orphans' psychosocial problems.

#### **5.3.1.6. Need for dealing with negative emotions**

Closely related to AIDS orphans' need for love and belonging is their need for dealing with negative emotions, which if unresolved, often lead to psychological problems. A problem mentioned by the caregivers is that orphans very often and easily cry. During her first interview, Mama said: "*One of the things is that they cry often – even if something small happens to them. Maybe they misplace their things and then they look for it and they don't find it – they just cry, and say, because there are so many people here, and things like that.*" These children may also cry when they remember past trauma and abuse they have not managed to deal with, such as the

one girl who did not have clarity about her surname: *“Sometimes she was crying when she would think about that she does not know her real surname and things like that.”*

Confusion and unhappiness cause orphans to use the emotional outlet of crying. AIDS orphans’ despondency and sense of hopelessness due to the loss of their parents also make them very vulnerable, as was the case with the following child at the care centre: *“The other one was crying the other day, and she (someone) asked why, and she said it’s because it’s so sad to – lose the parents like that and they just feel like they don’t have a future”*. One of the older caregivers, a grandmother, related that *“most of the children cry easily because they, they always feel that you are doing this to them, or if you try to help them, because you are not – like – their real mother”*.

AIDS orphans are generally not very stable emotionally. The researcher asked a caregiver what she believes to be the reason for the children’s short-temperedness and frustration. The caregiver replied that she finds it very difficult when children display emotionally unstable behaviour. She stated: *“..it is caused by – sometimes when they think of their parents. They get short-tempered or even cry, and then sometimes, she’ll ask them: What’s the problem? And they will tell her that they miss their mothers – so...”*. The same caregiver also explained that it is really difficult for her to see the children crying. She said *“it’s heartbreaking when the children cry when they miss their parents. That’s when it’s really difficult for her.”* Another elderly caregiver confirmed that the children cry easily, and easily get upset or irritated.

One may rightly assume that the negative emotions the AIDS orphans experience may be attributed in part to the fact that they struggle with pent-up emotions and anger towards family members who have mistreated them. Another cause may be their sense of being overwhelmed by their whole life situation and having to deal with life by themselves, which is an emotional burden not meant to be carried by children of such a young age. The feelings of despondency which some of the children experience at the deaths of their parents have been illustrated by some of the quotes mentioned beforehand. The prospect of a life without a future causes children to feel helpless and depressed. One of the caretakers said that *“many of them come here with depression”*. Depression in children should be taken seriously seeing that *“depressed children may be unable to take part in school activities or look after themselves properly”* (Foster, 2002:502).

One of the younger caretakers explained how she notices when a child is depressed:

*“She says yes, she notices it, they are depressed and they can get, you know...she says, she notices with some of them – how she recognises that they are depressed – the child will just sit there – and stare at one point and not do anything – and then she will call the child, maybe even for the third time, and then the child will wake up, and she will say, please go and fetch something for me, and sometimes they will not even hear that she said, “Go and do this and that”.*

This example illustrates that the orphans struggle to face the reality they are confronted with and are in danger of retreating into their own worlds unless they are given hope for the future. The orphans may also struggle to perform day-to-day tasks successfully as well as battling to concentrate on their schoolwork, which may even lead to greater feelings of despondency.

In Chapter one of this dissertation, it was mentioned that *“there is a need for further exploration of variables affecting the psychological health”* of AIDS orphans. Mueller, Alie, Jonas, Brown and Sherr (2011:57) also say that there is very little evidence available about the psychological health outcomes of orphans and vulnerable children. In the light of these facts, the psychological health of children infected with and affected by HIV/AIDS, is now a very important point on the research agenda (Mueller *et al.*, 2011:57). This fact is evidenced by the rising number in articles that are being published on the subject in very recent years (Cluver *et al.*, 2010; Mogotlane *et al.*, 2010; Cluver & Orkin, 2009). During the course of the present study, some very authentic voices were given the opportunity to speak on the needs of AIDS orphans and they were thus enabled to assist in raising public awareness of the needs of AIDS orphans in South Africa.

Li *et al.* (2008:147) once again confirm that little attention has been given to developmental and psychosocial needs of AIDS orphans. Li *et al.*'s (2008:147ff) contribution to the field of research on the needs of AIDS orphans is particularly valuable seeing that they have identified breaches in the literature, and suggest that future studies should focus on the mental health of AIDS orphans. Furthermore, they pinpoint individual factors that cause grief, and among others, look at the long-term impact of attachment with caregivers on the psychosocial well-being of AIDS orphans. These aspects relate very much to the focus of the present investigation.

#### **5.3.1.7. Physical/material needs**

*“Programmes that address physical needs whilst ignoring psychosocial needs are likely to have only limited effect”* (Foster, 2002:502). Foster (2002:502) mentions that most interventions in Africa have focused on the socio-economic needs of children or orphans and not on their

psychosocial needs. Strictly speaking, the main focus of the present study is not on the physical/material needs of AIDS orphans. In a third world context, however, the aspect of physical and material needs is mentioned so frequently that it cannot be ignored. The implications of physical/material neglect for the everyday psycho-educational functioning of a child can be very serious. Children's psychological state of mind may be considerably influenced by the available financial and material resources. In the light of the fact that the AIDS orphans, especially at the beginning of their orphanhood, often complain of illness, adequate medical support as well as provision of finances to take children to the clinic or hospital when necessary, is a definite need.

When the researcher inquired about further support that care centres need, one of the foremost needs was financial support, especially at the care centre where the AIDS orphans are not sleeping over. Financial support will assist in meeting the orphans' physical and material needs. The orphans' outward appearance in terms of their general attire plays an important role in the degree of acceptance that they experience from their peers at school. Seeing that orphans are at an increased risk of bullying and stigmatisation, these aspects simply cannot be neglected. One of the younger caretakers who is an orphan herself, mentioned that the outward appearance of orphans is an important factor in their socialisation with their peers: *"She really sees needs in these children. First of all, she just notices the clothes. First of all they do need to get clothes now and then. Because you see, sometimes, they sing in the choir, and you wear a shirt that is quite old, and you just feel off, that some of the children are looking nice and you are looking bad."* Naturally "looking bad" will negatively influence the children's self image, their sense of self-worth, in comparison to their peers. Since most of them do not belong to a particular family group, the foremost social group with whom they can compare themselves is their peers.

Medical needs, especially concerning eyesight, were also mentioned. One caregiver stated that some of the children have a problem with their eyes which seems to be related to the heat in the area. This problem causes the orphans to struggle with their schoolwork. Some of the children complain about headaches which might be related to the problems they experience with their eyes. A particular child, one of the caretakers mentioned, has a more serious problem with her eye muscles, which prevent her from seeing properly at school, especially when work is written on the chalkboard. Her handwriting is also unclear because of the problems with her eyes.

A very primary need of the orphans, which is also the care centres' most pressing need, is the provision of food. This need is more acute at the day care centre where the children cannot sleep

over. The problems related with inadequate nutrition are clear and need not be elaborated on. It has been mentioned that failure to provide children with food (as sometimes happens within the extended family) may lead AIDS orphans to resort to crime. In order to cater for this most primary need of these children, the care centres are dependent on donations (money to buy food, or food donations). It was also previously mentioned that more physical resources (e.g. toys, games and other educational material) are necessary to stimulate the children and to distract them from the emotional turmoil that they are experiencing.

When the physical resources of the care centres are considered (see photographs on CD in Appendix J) it is clear that these centres offer the most rudimentary physical resources to the orphans, but in spite of this they manage to render invaluable support to these children.

Another depressing point which Hearle and Ruwanpura convey, is corruption and confusion about the financial means and grants provided by the government for the support of AIDS orphans (Hearle & Ruwanpura, 2009:427ff). One of the caregivers also mentioned the misappropriation of grants by families of AIDS orphans: *“there is just one child that came to her recently, and she's told her that at home, she, she was registered for a grant from the government, but the families just take the money for themselves. And they don't keep anything for the child, maybe for the future as well. Like after matric – they would need to go to the university, that money can help, but whenever she asked them for something at least, or even a school uniform, they will say they don't have money. But she can see that they are buying expensive things, and that sort of thing with that money.”*

The present study gives the impression that the extended family system is by no means always the ideal environment for the AIDS orphans. It also seems that the additional financial and emotional strain placed on families may play a role in and lead to some of the abusive behaviours which orphans experience. Hearle and Ruwanpura (2009:428), confirm that *“despite the rhetoric surrounding cohesive communities, the day-to-day reality of the caregiver-orphan relationship as uncovered by this study points to fractures, stresses and strains in existing community networks”*.

A great deal has been said to elaborate on the needs and the situation of AIDS orphans, also in the light of literature available on the topic. The literature on bereaved children or children orphaned by HIV/AIDS focuses more on the problems these children have (Cluver *et al.*, 2010; Cluver & Orkin, 2009; Li *et al.*, 2008) rather than suggesting positive care procedures that can

assist in fulfilling these children's needs, such as giving them love and care. The present study has assisted the researcher in gaining a measure of insight into how certain qualities of care, as illustrated through the day care centres, construct positive development in AIDS orphans.

In summary, one can say that the general picture of the vulnerability and the neglected state of AIDS orphans as portrayed by the literature has been confirmed by the present study. Seeing that very little research has been conducted so far on the psycho-educational needs or psychosocial needs of AIDS orphans, this study has significantly contributed to a particular and far more detailed and personal image of the psycho-educational needs of AIDS orphans than is available in literature. Personal voices of the people with an intimate and day-to-day experience of AIDS orphans' needs have personalised a matter, which cannot be addressed in a mechanical way, but needs to rest on the perceptions and findings of those who most closely experience the phenomenon at hand.

### **5.3.2. Factors impeding the psycho-educational needs/development of AIDS orphans**

Two factors that impede the psycho-educational needs/development of orphans emerged from a data analysis of the information gained during the interviews with the caregivers, namely abuse and neglect.

#### **5.3.2.1. Abuse**

The interviews with caregivers revealed that AIDS orphans are subject to physical, sexual as well as emotional abuse. One of the younger caretakers, who is an orphan herself, related that *"she was very depressed and worried and abused and she didn't know where she can find a place – just to rest, or – to stay away from all those troubles"*. One of the caregivers at site number 2 stated that *"the children are short-tempered, because they feel pity for themselves (...) because of the abuse as well, they feel as if they are worth nothing, so..."* The fact that the AIDS orphans feel as if they are worth nothing indicates emotional abuse in the form of people or relatives telling them that they do not belong. Some of this is also referred to in paragraph 5.3.2.2. on neglect. One of the caretakers stated the importance of distracting orphans from the situation at home, suggesting that they experience emotional pressure: *"...many times they will just call them, and give them food, or ask them to do something, just to forget for a while – you know, what was happening at home – the stress that they have"*.

AIDS orphans get abused sexually. Some aspects referring to abuse have already been mentioned when discussing the AIDS orphans' needs. *Siyabonga*, one of the caregivers who has

close contact with some of the orphans says that *“There are quite stories about that – the first one is that have been abused – sexually, like raped, but then – Zulus are quite different from white people. They wouldn’t like – come out and be against that family member who does that to a child. You will get that the child will report about the problem, but maybe one of the family members, even the mother of the person who’s raped the child, will say, no, no, no, I don’t know nothing about that – don’t start speaking about that...”* This quote clearly indicates that identifying those who sexually abuse the orphans might be very difficult and is therefore an indication of the need to remove the children from sexually abusive conditions.

Physical abuse may take place in the form of guardians deliberately discriminating against the AIDS orphans when it comes to providing them with food. *Mama* recounts the following: *“One of the children had to stay with her sister – who was married, and then they said as the family of her husband, and then this child got very abused because her sister’s mother-in-law said – she must not eat – the children of the house must eat first – and then she must come last – so every time she will think about that, and that really abused her so much, and that she was so thankful to come here, because she was free to eat whenever she wants, and openly”*. This quote has been used beforehand, but it once again demonstrates the way in which AIDS orphans may experience physical abuse in the form of wilfully depriving them of what they need. Physical abuse may also take place in the form of physical demands that are being placed on young children. One of the older caretakers at site number 2 stated that *“some of the children are abused by their family members. Sometimes they have to go and fetch water before they go to school.”* It may also be mentioned again that one of the caretakers, who is an orphan herself, related that *“she even has a scar somewhere, because they used to beat her”*. Obviously, the kind of beating this child received went far beyond usual ‘hidings’ which children in healthy families may also be subject to. Since the beating caused a scar it must have been considerably violent in nature.

#### **5.3.2.2. Neglect**

Neglect which AIDS orphans suffer takes place in the form of emotional, physical and social neglect. It is inevitable that in a context, where relatives *“say all kinds of things”* (quote from a young caregiver) against orphans because of their status, orphans are neglected emotionally in that they are not given love, care and comfort in their debilitating situation. The consequence of such coldness from relatives towards the orphans may lead to stress, as one of the caregivers recounts: When she reached the day care centre, she came there *“with stress”*. The AIDS orphans meet with adversity, unfriendliness, and often have to fight their way through life. The lack of love can be seen by the way in which family members treat orphans who inquire about

their background. One of the caregivers said that her family or relatives “*refused to tell her exactly what happened...*”. This caretaker (an orphan herself) related that at some point “*the family members told her to go away*”. The lack of love and care/comfort which orphans face is a serious form of emotional neglect. Besides the deliberate abuse that is inflicted on children, they are robbed of a warm, loving and caring environment.

The fact that families often do not possess the financial means to look after orphans also leads to all kinds of forms of physical neglect. Orphans may not receive proper clothes. One of the younger caregivers related: “*She really sees needs in these children. First of all, she just notices the clothes...*” A caregiver also related that when the relatives did not want her anymore, since she was an orphan, they told her “*that there was nothing, nothing belonged to her in that house, so she must see where she will go*”. This suggests that orphans frequently suffer from physical neglect in that they are expected to make their own livings. Another quote which indicates physical neglect is the following: “*She went to school without eating, or they just gave her the leftovers*”. Another young caregiver, also an orphan, related that “*before, her mother died first and her father took in a stepmother, and that’s when the problems started. Many times she had to go away and sleep by the neighbours because she did not like her. Nobody made sure that she had clothes and nobody really took care of her, she was like on her own.*” This example suggests physical as well as social and emotional neglect, since the orphan could not feel part of the family anymore and the stepmother had a negative attitude towards her. As is demonstrated here, orphans may not receive proper food, and it was mentioned beforehand that one of the orphans had to break in at his neighbours, in order to eat. Social neglect takes place in the form of denying orphans a place in their community, or in the family where they reside. By treating them as outsiders, they do not receive the opportunities to socialise normally as other children would be able to do.

### **5.3.3. How the day care centres meet the psycho-educational needs of AIDS orphans**

On the basis of the information gained from the interviews with the caregivers and the personal observations of the researcher, it became evident that the care centres provide a family-type of environment to the orphans. One of the caregivers referred to this in the following way: “*(...)..they mix up with other children. And here is the new Mama of the house...*”. One of the older caregivers said the following: “*She’s sometimes amazed, there are – they have a very close relationship with the children. Because many of them were abused before, and when they come here, they really find love. Like now – if she – she wasn’t here, but if they could come first before her, from school- they’ll do whatever they need to do, and then when she comes, maybe from the*

*gate they will run to her, and try to help her if she's got plastic bags...".* The caregiver who reported this experience also emphasised that loving the orphans was the most important responsibility of working with them. She said *"she really loves the children – all of them – they are really – like in her heart..."*.

It also became apparent that caregivers assist orphans to accept their present situations while at the same time supporting their growth and development in a non-threatening environment. One of the younger caregivers related that *"what they try to do is to, if the child comes here, they try – that she first accepts everything as it is(...)because what is more important is that the child get help, and that she understands everything, and that she feels, you know, as a human being as well"*. One of the younger caregivers also mentioned that *"many of them (the children) always say that they are happy to be here"*. This suggests that the children or AIDS orphans experience the day care centre as a care-free place.

The care centres assist orphans to deal with their negative emotions and to come to a new understanding of themselves. *Mama*, one of the older caregivers related that the AIDS orphans *"even start to understand themselves in their situation, and to know that they are like -normal people as well - like if you are a girl, you understand that I am a girl, I am supposed to live like this- eh - how am I supposed to take care of myself and things like that"*. Loving the children seems to be a very important prerequisite in enabling them to speak about negative emotions. *Mama* related: *"Because she's seen the results, you know, of – showing love to the children, because, after some time, they, they will see them opening up – like, being free and able to speak to one another, and have a good relationship, ja, with each other"*. The care centres also assist the AIDS orphans to gain a more positive perspective on the future. One of the caregivers stated that orphans know they will be taken care of at the centre; this means they will experience a more care-free environment: *"Then as they came here, there will be more nice things for their future, and they will live nice here, they will be taken care of"*.

The care centres also play an important role in the spiritual development of the orphans. The children learn to understand God as a caring Father and this is instrumental in assisting children to accept the loss of their parents combined with the knowledge that a powerful heavenly Father will be there to care for them. In this regard a caregiver said:

*"One of the spiritual – ehm, mental needs is that, when the children come here, they have this thing on their minds that they don't have parents anymore, it's like they have nothing left, and*

*there is nothing that will be coming in future for them, and then – but they teach them that God is actually more important than their parents, then from there, they start to understand life better than before.”*

The care centres provide a stable emotional platform for the children to work through the deaths of their parents, an important need that was stated previously. One of the caregivers stated that *“they like have a platform here for them to speak openly – they don’t force them you know like ‘You must speak now, what is wrong with you?’ They give them time, and they will read Bible to them and – just like, maybe give, teach them about the example of the Lord Jesus, how He forgives each and everybody, and then they just leave it with them, to come to them...”*

It must be noted, however, that this kind of in-depth support is only possible at the care centres where the AIDS orphans are able to sleep over. Caregivers at the smaller centre repeatedly expressed the desire to offer the children the opportunity to sleep over at the care centre as this would help them to understand the orphans better and to render more adequate support. Here are some examples of what caregivers from this other centre, where children cannot sleep over, said:

*“Because the children doesn’t sleep here, they get affected as well with what is happening at home...”*

*“She (caregiver) says it’s easier to identify their problems if they stay – they would stay here (...) she says that she do try to speak to some of them, but they not open – they just say there is no problem.”*

**Researcher:** *Would she like the community to get more involved?*

**Caregiver:** *They would be happy if they can build a house for the children.*

At the care centres where the children can sleep over, the peer group also renders valuable emotional and social support since children are sometimes more ready to speak to their friends about problems than to older persons, as has been mentioned before. Children that are new at the care centre are also encouraged by those who have been there longer and who seem to be care-free and happy.

Younger participating caretakers, who have been orphaned themselves, stated that a main advantage at the care centre is the opportunity for counselling which they receive there. In spite of their difficulties in opening up, orphans seem to have a great need for speaking to someone about their problems and getting rid of their burdens. The caregivers act as key persons in assisting children to work through problems and grief and the AIDS orphans find a new home and a sense of belonging somewhere.

Other children who have been helped may serve as role models for new AIDS orphans and the care centre also assists in removing AIDS orphans from abusive conditions and provides them with a safe haven while supporting them in their most immediate physical needs, such as food, clothing and some amount of medical care. It should be stressed again, however, that the care centre where the children *are able to sleep over* is in a better position to fulfil the orphan's needs.

#### **5.3.4. Summary of findings**

The main needs identified in the AIDS orphans during the course of this study where their need to socialise and communicate, their need to work through parental death, their need for acceptance, their need for security and care, their need for love and belonging, as well as their need to deal with negative emotions. Furthermore, AIDS orphans' physical needs came to the fore which may include medical needs as well. An important distinction emerged when comparing data from the two day care centres where interviews have been conducted: the first centre, where children are offered the possibility to sleep over if they need to, seemed to be able to adequately meet most of the AIDS orphans' needs that manifested in this study. While the caretakers at the second centre were willing and tried to assist the orphans at their centre as best as they could, they did not manage to build up the same kind of supportive relationship which the caregivers have with the orphans at the first care centre. The caregivers seemed to attribute this problem to the fact that the children are not able to sleep over and permanently stay at the centre. The study seems to support the stance that removal of the AIDS orphans from the extended family, at least for a period of time, may be necessary in order to assist them psychologically and protect them from conditions of abuse which, according to evidence found in this study, is at the order of the day.

#### **5.4. DISCUSSION OF FINDINGS**

In Chapter 1, the fact that the extended family system may not be able to cope as well with the rising number of AIDS orphans in Africa as is often expected, was indicated (Lalthapersad-Pillay, 2008; Heymann *et al.*, 2007; Stover *et al.*, 2007:21). Mogotlane *et al.* (2010:24) confirm

the fact that “*families and communities are currently unable to cope with the effects of HIV and AIDS with special emphasis on the care and support of the affected orphans and vulnerable children*”. Mogotlane *et al.* (2010:24), who conducted a study analysing the situation of child-headed households in South Africa, explained that the data collected in the course of their study demonstrated that children’s rights were being compromised. Mogotlane *et al.*’s findings are very much in line with what has been discovered in the course of the present study. Not only have AIDS orphans’ rights in South Africa been seriously compromised; the present study also found that a considerable amount of evidence exists that children’s needs are being seriously neglected, and frequently, deliberately assailed and set at naught.

Since the extended family system can no longer carry the burden of the rising number of AIDS orphans without concrete support, and given the problems which arise from the placement of AIDS orphans within the extended family system, other forms of accommodating AIDS orphans need to be taken into consideration. A study carried out in poverty-stricken communities in China shows that problems regarding placement of AIDS orphans in kinship care is not unique to Africa (Hong, Li, Fang, Zhao, Zhao, Zhao, Lin, Zhang & Stanton, 2011:121). It seems that one of the care centres where investigations took place during the course of this study may be exemplary of a model which could effectively work to support AIDS orphans during their times of difficulty and most urgent need. Caregivers at the second centre who desired to provide orphans with a place to sleep suggested that orphans could still go home to visit while staying at the care centre. While this may provide an effective model of intervention without removing AIDS orphans completely from their natural environment, ‘visiting home’ will have to be carefully monitored, especially in the case where sexual and other forms of abuse in the family is taking place, as has been reported on in this study.

The aspect of child abuse has been mentioned several times with regards to the AIDS orphans’ needs. In closing, the aspect of abuse will be discussed in a bit more detail, since it’s implications for child development are so serious. Child abuse has occurred throughout human history (Empson, Nabuzoka & Hamilton, 2004:74) and is by no means unique to a developing country such as South Africa struggling with HIV/AIDS. Even in a developed region such as the UK, child abuse takes place in up to 5% of families (Empson *et al.*, 2004:73). Seeing that abuse tends to be hidden in nature (Empson *et al.*, 2004:78) the present study is particularly valuable in exposing abuse as it is taking place in some of the most remote areas of South Africa in a population group that is seriously endangered: the AIDS orphans. The voices of the participants as they appear in the present study are unambiguous. They speak their truths which is grounded

in their personal experience of life stories told by children under their care who are forgotten and neglected by a large part of society. Through their intimate involvement with the children, caregivers were often able to recount children's behaviour and words very precisely.

Defining child abuse is not an easy task, in the light of the fact that different cultures view abuse differently. Empson *et al.* (2004:79) also make clear that abuse is embedded in the context in which it appears. While citing various authors in an attempt to explain and define abuse, Empson *et al.* (2004:78) state that there are commonly accepted standards across cultures as to what constitutes abuse. Abuse involves any kind of child maltreatment or neglect, and diverse forms of physical, emotional and sexual abuse often occur together (Empson *et al.*, 2004:78). Empson *et al.* (2004:78) note that abuse need not necessarily take place only in a relationship where the one person is responsible for the well-being of the other. The conclusion is that abuse can take place between an older and a younger child, wherever a power difference exists, and unhappily, abuse tends to take place between related people (Empson *et al.*, 2004:78). Bullying of AIDS orphans by their peers who are in a better position than they themselves are, and thus the stronger counterparts, can also be classified as a form of abuse of the AIDS orphans, that may considerably impede a child's development. The need exists for community intervention on a larger scale in order to reduce the stigma attached to HIV/AIDS.

Any form of child abuse not only harms the child's emotions and his/her physical condition, but it also robs the child of a secure and care-free environment in which he/she can develop freely. Hughes (1999:161) maintains that a child's play occurs best in a stress-free environment. Children who are constantly bombarded by stressors are unable to freely and confidently explore their environment. Play activities and toys are crucial to a child's development as they provide kids with opportunities to develop physical skills, take on different roles and develop their creativity and cognitive functioning (Hughes, 2002:320). The different developmental tasks which take place during childhood have been elaborated on in Chapter 3. Hughes (1999:161) documents evidence that children who have been maltreated are less imaginative when playing as well as less mature cognitively and socially. Interestingly, one of the participants in the present study described the example of two children at the care centre who only watched the other children's play instead of playing too. Generally, the AIDS orphans' tendency to '*become sick often*' and their reluctance to talk, signifies withdrawal from enjoyable social situations in which play and learning could possibly take place. One of the caretakers, however, suggested play as an activity which can assist children in forgetting their misery for a while and a welcome distraction before their return home into their ever-stressful environments. The grandmother

concerned literally stated, *“the children really like to play here, because, I mean – what – they can do much things with them during the day. They need more toys here to play with the children, so that they can forget everything for a while and then go back.”* Play in the given context may offer and serve as therapy for children who have been abused. Literature shows that children who lose their parents may lose their childhood altogether, as they have to become adults prematurely (Wood *et al.*, 2006:1927).

What about more specific abusive experiences which the AIDS orphans go through? Does literature offer any evidence for the abusive experiences, documented in this study, reported to take place among AIDS orphans in South Africa? Mueller *et al.* (2011:57) mention AIDS-related stigma, community, and household violence as risk factors negatively impacting on the psychosocial health of children affected by HIV/AIDS in South Africa. Once again, this illustrates the HIV/AIDS’ orphans urgent need for security and care. Ardington and Leibbrandt (2010:507ff) question the idealistic notion of *“there is no such thing as an orphan in Africa”*, making clear that orphans tend to have poorer scores on developmental outcomes than children who are not orphaned (Ardington & Leibbrandt, 2010:508). Cluver *et al.* (2010:793ff), who conducted a study about *“risk and protective factors for bullying victimisation among AIDS-affected and vulnerable children in South Africa”*, state that children who are already highly vulnerable and disadvantaged by their contexts through abuse or violence in the home, living on the streets, or experiencing stigma related to HIV/AIDS, are also susceptible to forms of bullying. All these authors give us hints with regards to abusive and neglectful conditions which AIDS orphans might be experiencing, and this in turn emphasises the orphan’s need for security and care. As was mentioned in Chapter 2, Hearle and Ruwanpura (2009:423) confirm that a rise of HIV/AIDS infected people who are part of the adult population has had the tragic consequence of a heightened number of children who are uneducated, vulnerable, and malnourished. All these outcomes may partly be due to conditions of abuse. AIDS orphans’ deficiency needs (Ormrod, 2008:388) are compromised which means they are much less likely to have their growth need for self-actualisation met (Ormrod, 2008:388).

The aspects of vulnerability and malnourishment documented by Hearle and Ruwanpura (2009:423) previously, concur very much with the findings of the present research, where AIDS orphans do not receive adequate food, even at the families that take them in. They are particularly vulnerable, being abused, and beaten for matters such as inquiring about their surname. The picture of the life of the average AIDS orphans portrayed by the participants of the

present study illuminates the general aspects noted in the literature which are considered as risk factors to the lives and developmental needs of AIDS orphans.

It was mentioned by the caregivers in the course of this study that AIDS orphans tend to be depressed. One of them actually stated “*many of them come here with depression*”. The question arises as to whether the AIDS orphans’ symptoms of depression are related to the abusive experiences they undergo, if not to all the other life stressors they face. Li *et al.* (2008:148) state that children are in particular at risk of developing complicated symptoms associated with grief because of their increased vulnerability (mental immaturity and emotional dependency). Li *et al.* (2008:152), in referring to the fact that few studies in resource-poor countries have focused on psychological problems of AIDS orphans, nevertheless maintains that data available from Africa yields the impression that children orphaned by HIV/AIDS suffer from a higher incidence of depression, than children orphaned by causes other than HIV/AIDS or children growing up in healthy families. Stroebe, Abakoumkin and Stroebe (2010:85) refer to depression and sadness as significant factors accompanying grieving reactions, in spite of their arguing for the fact that depression is not the most important reaction to the loss of a loved one. Depression remains a symptom of grief, however, that may be expected and has been observed as accompanying reactions to parental death.

Lastly, the finding that AIDS orphans may be helped better when taken out of the extended family, as this present study indicates, seems to be supported by what Foster (2002:503) says: If psychosocial needs are not addressed, long-term emotional and behaviour disturbances may be the result (Foster, 2002:503). This is explained in depth by the following quote from Foster (2002:503):

*“Psychosocial needs are frequently overlooked because of the difficulty in recognizing psychological reactions. Many people lack an understanding of child development and appreciation of children’s psychosocial needs.(...)Psychological reactions may only become apparent months or years after parental death. Consequently, the link between stressful events and corresponding reactions goes unrecognised. Different children exhibit different behaviours, and symptoms are often intermittent. Children may one moment display adult-type grieving behaviour such as weeping and the next moment engage in seemingly normal behaviour such as play. This apparently contradicting behaviour is baffling to adults. Teachers or other adults who fail to understand that fluctuations in behaviour are symptomatic of psychological distress may*

*respond by punishing, rejecting, or simply ignoring affected children, thus compounding the problem” (Foster, 2002:503).*

## **5.5. CONCLUSION**

The following psycho-educational needs of AIDS orphans surfaced during the course of this study:

- the need to socialise and communicate
- the need to cope with parental death
- the need for acceptance
- the need for security and care
- the need for love and belonging
- the need to deal with negative emotions
- physical and material needs

Aspects of abuse and neglect, which were frequently mentioned, clearly act as factors which inhibit and impede AIDS orphans’ psycho-educational development. Through neglect and abuse AIDS orphans are robbed of a carefree and non-threatening environment in which they can develop freely. Additional stressors are added to their lives, which makes healthy development extremely difficult.

The study also showed that if AIDS orphans can be given the opportunity to sleep over at care centres, a large spectrum of their needs can effectively be met, since caregivers can continuously observe children and their behaviour fluctuations and then find more effective ways to address the children and their needs. These conclusions were reached after in-depth discussions and interviews with the caretakers of the AIDS orphans.

## **5.6. RECOMMENDATIONS**

In the following section, an attempt will be made to recommend further support that should be given to AIDS orphans in day care centres to enhance their psycho-educational development. In confirmation of the psycho-educational needs of AIDS orphans uncovered in the course of this study, Delva (2010) notes: *“AIDS orphans face far greater financial, educational and psycho-social challenges to their development than their peers with healthy living parents. Development organisations and research institutions have traditionally focused their efforts on the physical and material needs of these orphans. In contrast, efforts to measure and counteract the impact of parental bereavement on children’s social and psychological well-being have only commenced*

*recently. Anecdotal reports indicate that AIDS orphans often lack social support and that abuse and neglect of AIDS orphans by both the extended family and the broader community is not uncommon.”*

This quote emphasizes that support in the form of financial assistance will not be sufficient to aid AIDS orphans' needs. All policy-making pertaining to the lives of children, their education, and upbringing in South Africa will have to take into account the more than a million South African AIDS orphans (Anon, 2009b). Chapter 2, in particular paragraph 2.4.1. on the early history of HIV/AIDS and AIDS policies in South Africa, explained how failure of effective HIV/AIDS policies on a national level in South Africa led to the subsequent disaster which we are facing today: an approximate 32% of children orphaned due to HIV/AIDS by 2015 (Baldauf, 2009). As this tragedy clearly shows, the national government will need to interfere by effective policy-making and implementation if AIDS orphans are to be effectively supported by thousands of caregivers across the country. On a regional or provincial level, this may mean a number of services will need to be provided and made accessible, as well as important key role players identified and enabled to provide the support to a massive number of orphans which South Africa needs to deal with, at present and in future. With these facts taken into consideration, the following recommendations on care centres will include factors that need attention on macro (national), meso (provincial) and micro levels.

On a national level South Africa will need decisive leadership, informed by generally accepted scientific practices in confronting the national HIV/AIDS epidemic. It seems as if president Zuma is paving the way for this to happen. In his speech during World Aids Day, Zuma promised an increased roll-out of antiretroviral drugs which the government under the former president Mbeki considered too expensive (Anon, 2009b). The national government will have to review past HIV/AIDS policies, and in the light of their effectiveness devise strategies that will inherently address the issues concerning HIV/AIDS and consequently, AIDS orphans in South Africa. For this to happen effectively, cooperation must be achieved between all stakeholders and departments on a national level. As Boutayeb (2009) made it clear, *“AIDS is no longer a crisis only for the healthcare sector. (...) The disease is impeding development by imposing a steady decline in the key indicators of human development and hence reversing the social and economic gains that African countries are trying to attain.(...) Being at the same time a cause and consequence of underdevelopment, it constitutes a challenge to human security”*.

Instead of placing the AIDS Programme Director in the Ministry of Health, as was done in the past, he/she should be placed in the President's Office, since HIV/AIDS is an issue which concerns all sectors of South African society and not merely the Department of Health (AVERT, 2011). The systems which will be put in place and the lines of communication between role players are what will make out a successful fight against HIV/AIDS on a national level. HIV/AIDS and the resulting AIDS orphans in South Africa must receive a multi-sectoral approach, and all the departments involved must communicate with each other on a continual basis. After consensus has been reached on an approach at national level, it will be of crucial importance for the different departments to report back and be accountable to each other on a continual basis in order to be able to update and optimise approaches according to the most current developments. Such accountability and communication on national level is of crucial importance if real assistance is to be provided to AIDS orphans in South Africa. National coherence will also lead to more successful and purposeful distribution of resources to provinces, for the simple reason that communication will inform national role players of the more particular situations and needs within individual provinces. Communication is needed among national stakeholders, but also between national decision-makers and provincial role players, particularly in the political realm. Finally, the government should work together with civil society organisations (CSO's), and not exclude them from action taken by the state (Evenson & Stokke, 2010:152, see chapter 2 paragraph 2.4.1.).

On a more provincial and regional level, there is a broad spectrum of needs that need to be addressed in order to be able to provide better support to AIDS orphans in day care centres with the aim of enhancing their psycho-educational development. In the first place, the Department of Health will need to train staff in order to be able to render assistance to AIDS orphans, their families, and care centres in rural areas such as those identified for this study. The KwaZulu-Natal Department of Health (2011:291) does indicate Human Resource Development as one of their main services provided in their annual report. The Department of Health will also need to assess the availability of medical services and clinics in the vicinity of care centres for AIDS orphans in order to erect additional clinics and provide services where necessary. Some care centres may benefit from a permanent nurse or medical staff member. These undertakings will need to be included in the budget programmes of the Department of Health of KwaZulu-Natal. It will also be of importance to consider the care centres for AIDS orphans when mobile clinics are being arranged, whether this is done by state-supported initiatives or privately funded organisations. By co-operating with civil society organisations, the Department of Health can be better informed of when such actions take place, and therefore attempt to provide medical

assistance to those most in need. Co-operation with and knowledge of private initiatives is of particular importance for the Department of Health, since most of South Africa's health care professionals work in the private sector. In contrast, South Africa's public health care sector is "*under-resourced and over-used*" (Anon, 2011).

A further aspect which needs definite attention from the provincial government is the aspect of child abuse and neglect as it takes place in the lives of AIDS orphans, especially since this seems to be a very common occurrence in the context of HIV/AIDS (Delva, 2010). The Department of Justice ought to make the occurring child abuse and neglect an urgent subject of attention (see also Freeman & Nkomo, 2006:309-310). Social workers may be needed to identify children living under conditions of abuse and neglect, and then legally removing them from those conditions. Another problem is that the growing number of orphans can no longer be fully supported by the extended family system (Lalthapersad-Pillay, 2008:148) and placement strategies for AIDS orphans in caring and supportive environments will have to be worked out and, where necessary, enforced legally. The fact that abuse occurs in the extended family may also serve as an indicator of the fact that the extended family system is under immense strain and in need of support from the state. Shabalala (2007?) hints at the fact that civil society needs to be engaged in connection with supporting victims of crime. The fact that so many AIDS orphans suffer abuse means they will have to be considered in future as an important subgroup among crime victims in South Africa.

The caregivers of AIDS orphans, having to deal with emotionally very challenging matters, are in need of emotional support themselves. It is advisable that caregivers, especially those counselling the AIDS orphans, be given the opportunity to receive training in counselling. Contacts with a social worker in order to receive advice on how to handle challenging matters may also be advisable. Some of the caregivers themselves may not have received proper schooling, and therefore, may struggle to participate in courses on counselling as well as being incapable of gaining access to information which may be of assistance to them. This is where the Department of Education should step in and provide opportunities for adult education, so that caregivers can equip themselves with the necessary skills which they need to assist the AIDS orphans.

Another point which may be regarded as the responsibility of the provincial government, is the improvement of the infrastructure at day care centres. In the present study it was found that roads leading to the care centres were in an extremely bad condition. At some places the road appeared

to be non-existent. This would make it very difficult for outside assistance to reach the AIDS orphans. The need for better roads, and consequently more accessibility, is imperative and may be considered a responsibility of the Department of Transport, the Department of Human Settlement and Public Works, and the Department of Social Welfare and Development. The Department of Human Settlement and Public Works of KwaZulu-Natal states that “*the government has currently invested billions in infrastructure delivery*” and that the programmes of the Department illustrate the “*commitment of the Department to priority groups*”. (Department of Human Settlement and Public Works, 2011). In future the AIDS orphans will have to be included in these priority groups. Aspects of infrastructure at care centres are not limited to roads. Basic service delivery is also inadequate. Neither of the centres in this study has electricity, and only one centre has running water, but no hot water. Very poorly equipped and constructed buildings are indicative of a lack of financial support at care centres to improve conditions of severe poverty. The Department of Social Welfare and Community Awareness should assist here since one of the services they claim to offer includes “*drop in services*” which are said to be available to “*give care to those families, children and youth that are affected by HIV/AIDS*” (Department of Social Welfare and Development, 2011).

Finally, community upliftment needs to happen on a larger scale in the areas where care centres for AIDS orphans can be found. Communities in which care centres for AIDS orphans are situated are marked by poverty and a lack of economic development. The consequence of this is that very little future opportunities exist for the orphans and also that all assistance to care centres has to come from the outside. This is a negative state of affairs which may lead to care centres being isolated from the surrounding community, and since assistance has to come from sources outside of the community, it may not reach the care centres in time. If community members could be involved in farming projects, care centres could begin to generate a source of income for themselves within their own community. The Department of Agriculture and Environmental Affairs may be involved in this regard (Department of Agriculture and Environmental Affairs, 2011).

The aspects mentioned on macro and meso level which need to be taken into consideration in order to better facilitate the psycho-educational development of AIDS orphans at care centres lead to changes which need to occur on micro level, at the individual care centre level. Many aspects that need attention and can contribute to support for AIDS orphans at care centres have been mentioned.

It was not easy to elicit responses from the participants in terms of further support that care centres would need to meet AIDS orphans' psycho-educational needs, as most of the caregivers described the needs of the care centres in terms of financial support. During the course of the interviews, one of the caretakers stated that *"It's very difficult for her when children cry because they are missing their parents"*. As has been mentioned earlier, this suggests that some basic training on how to counsel children may be helpful to caregivers, especially in the light of the fact that some of them are illiterate and cannot access useful information by themselves. Emotional support for caregivers given by social workers who could visit the care centres from time to time will be valuable.

The caregivers generally seemed to enjoy their work, and stated it themselves. The caregivers at the care centre where children cannot sleep over, strongly emphasised the need of providing the AIDS orphans with a place where they can spend their nights and stay over. This necessitates new buildings.

One of the caretakers at the 'more privileged centre' also mentioned the need for the children to be taken on excursions, simply to broaden their horizons. The caretaker stated that someone had taken the initiative to take the children somewhere, and the children had benefitted from it. Such an undertaking may likewise serve as an educational opportunity for the children whose lives might have been revolving around the small community in which they grew up. This indicates that since AIDS orphans are often deprived of healthy homes, there may be a need to create educational opportunities for them. This aspect would form part of their educational development.

In spite of the fact that the caregivers mentioned the aspect of children from different backgrounds having to cope with each other at the care centres, they seemed to manage this aspect fairly well on their own. The emphasis remains on sleep-over facilities at the care centres as well as on assistance in revealing and addressing incidences of abuse which take place in their homes. Assistance with the orphans' schoolwork is also necessary, especially at the second care centre where some of the older caregivers did not receive a proper school education themselves.

In conclusion, it must be said that society at large needs to be made more aware of the fate of AIDS orphans in our country. If the general public is informed about the abuse that some of these children experience, it will be easier to identify cases of abuse among AIDS orphans so that the necessary psycho-educational support can be rendered to these children.

Psycho-educational support rendered to AIDS orphans in care centres should be based on extensive needs assessments in future, as was done in this study. This is of primary and pivotal importance. It follows that future research should focus on the particular needs of AIDS orphans, in order to plan effective community intervention programmes.

### **5.7. LIMITATIONS OF THE STUDY**

Unfortunately, the findings of the present study cannot be generalised to other settings. This is partly due to the fact that the present study is of qualitative nature; findings cannot be generalised to other settings since the sample size is small. A further limitation to the present study is the fact that the interviews were translated and then recorded (as well as transcribed) in the third person. This process may have caused important information to go lost or at least not to be put in the interviewee's exact words. Naturally, this is another factor which adds to the limitations of the present study. Nevertheless, the present study provided some very valuable insight into the phenomenon studied and was done with the aspiration is that future researchers will be inspired to undertake further research in this field.

### **5.8. CONCLUDING THOUGHTS**

The present study contributed towards a better understanding of the psycho-educational needs of AIDS orphans at two care centres. The study also provided evidence of the important roles that care centres play in the lives of AIDS orphans.

The following quote illustrates that the public at large should become better informed about the plight of AIDS orphans in South Africa:

*“Although awareness of the plight of orphans and street children is now growing, the magnitude of the problem has not been acknowledged by many players, such as ordinary citizens, government officials, churches and communities, and minimal literature exists that gives a precise overview of the problem”* (Chama, 2008:411).

The young generation of South Africa is crying out for our help and support. Young children are growing up without hope, and without a future as stated on the following page (Leclerc-Madlala, 1997:363):

*"We thought that with the new government we could relax, study, plan a future. Now AIDS is here to give us no future. Well we'll all just get it and that's life. We're cursed; we really are the lost generation."*

*(Zulu male aged 20)*

Let us run to our young people's aid.