"The emotional well-being, social adjustment and coping strategies of orphans and vulnerable children affected by HIV/AIDS"

Submitted in partial fulfilment of the requirements of the degree
Masters in Clinical Psychology

At
The University of the Witwatersrand, 2007

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Acknowledgements

Thank-you God for giving me this blessing; you have been with me all the way.

In order to accomplish this work, I had to make several trips between Johannesburg and Lusaka; an altogether expensive venture. I also had to drive to various places in Lusaka in order to get the work done and gather information. This would not have been possible without the very kind generosity of the following people, who care about Zambia’s children, as much as I do. I respect your request to not use your names, so I will just stick to initials. Thank-you my dearest friends and relatives, DB, JC, KS, JB, MB, MS, CL, MP, and CM.

To Vincent and Father Charles, at Loyola Productions, thank you for taking the time out to help me, even when you had other projects going.

Thank-you to the people at SCOPE-OVC, CARE International Zambia, and the University of Zambia research centre.

Thank-you to Gertrude and the ladies in the psychology department at the University of Zambia, your assistance was invaluable.

Thank you to the courageous children who made this study possible by allowing me into their lives; I will continue to pray that you all fulfil your dreams.

Thank-you to my various lecturers, and especially to my supervisor who went beyond the call of duty to help me through a very difficult year.

Thank you to my mother and father, and my brother Paul for encouraging me to continue and for believing that I could do this, even at my age! Lastly I would like to say thank you to my sister who opened up her heart and her home to me, you have been my rock, I could not have done this without you.

I pray that God will continue to give all of you His continued grace and blessings.
Abstract

This study looked at how children who are exposed to the impact of HIV/AIDS in their immediate families are affected and what coping strategies they employ. Research was conducted in Lusaka, Zambia, involving eight female and eight male Zambian children between the ages of thirteen and sixteen, as research participants. Separate gender specific focus group discussions were held, after which the recorded proceedings were transcribed and analysed using thematic content analysis. The study found that children experience socioeconomic difficulties, psychosocial deprivations, and insecurity as a result of parental death or illness. However, they are still able to find ways to survive and cope with their difficulties. State and private sector efforts have focussed primarily on addressing the socioeconomic needs of these children as this has been understood to be the most critical. The psychological impact of HIV/AIDS on children in Zambia, and the resultant needs that arise, will need to be tackled as a matter of priority.
1. Introduction

1.1 Aim & Overview
The primary aim of this research was to examine and explore how orphans and vulnerable
children (OVC) in Zambia are impacted by HIV/AIDS. The research attempted to gain insight
into the direct and indirect consequences of the children's changed circumstances stemming from
family vulnerability to HIV/AIDS. It focused mainly on emotional well being, social adjustment
and the coping strategies that these specific children employ.

The rate at which HIV/AIDS continues to spread and decimate the adult population of Sub-
Sahara Africa is alarming. Current statistics obtained from the Joint United Nations programme
on HIV/AIDS (UNAIDS) indicate the prevalence rate at 7.4% with an estimated twenty-five
million people currently living with HIV/AIDS. It is further reported that the region while having
only 10% of the world's population has about 60% overall, of people living with HIV. These
figures include children. In sub-Saharan Africa, about twelve million children have lost at least one
parent to HIV/AIDS; all these children are under the age of 17, with an overall number of forty-
eight million being orphaned. (UNAIDS 2006). It is therefore widely acknowledged that children
are becoming more vulnerable and will face greater risks.

This is especially true in a country like Zambia where the social welfare system is not adequate to
handle the situation, nor is there a social security system in place that could provide a safety net.
Statistics obtained from a joint UNAIDS/UNICEF report on Africa’s orphans and vulnerable
generations (2006) indicates the number of orphans under the age of 17, at the end of 2005, to be
approximately 1,200,000. The report highlights Zambia’s situation as follows:

In Zambia, for example, 20 per cent of all children were orphans in 2005, over half of them due to
AIDS, leaving a population of 11.7 million to support 1.2 million orphans. With one sixth of
Zambian adults currently infected with HIV and only about 25 percent of those in need receiving
antiretroviral therapy, AIDS will continue to kill parents – it took the lives of about 75,000 in 2005
– and increases orphan prevalence for years to come.

Past studies in Zambia have focused mainly on determining the social and economic effects of
HIV/AIDS on the population as a whole. With the exception of one specific study conducted in
2001(FHI, USAID, 2002), there is little evidence to suggest that the psychosocial effects of
HIV/AIDS on children have been investigated on a wide scale. This is understandable, when one looks at the current economic situation that obtains in the country: the more pressing issues of physiological and material needs have to be addressed first. It is important to bear in mind that these needs will continue to be the main impact for many children. (USAID, FHI, 2002).

It is believed that this study will make a positive contribution towards understanding the social, emotional and mental vulnerabilities that children are exposed to in relation to the condition. In addition it is hoped that the body of knowledge currently available may be usefully added to, and possibly, in conjunction with other material, may be used to help provide needed psychological services to children.

1.2 Definitions
For the purposes of this research the following definitions were employed:

AIDS _ Orphans
The World Health Organisation (WHO), the United Nations Children's Fund (UNICEF) and Joint United Nations program on HIV/AIDS (UNAIDS) have defined AIDS orphans as children who have lost their mother to AIDS before the age of 15, and may have already lost or will soon loose their father to the same illness.

Vulnerable Children
"A child who is at increased risk due to an ill parent, high level of poverty, or living in a household with orphaned children". (Banda & Tembo, 2001).

1.3 Research Questions
The following questions will attempt to address the primary aims of this research.
1. How does exposure to the impact of HIV/AIDS in their immediate family appear to have affected thirteen to sixteen year old Zambian orphans and vulnerable children?
2. What are the coping strategies employed by these children to deal with their problems?
2. Literature Review

2.1 Introduction
HIV/AIDS continues to ravage, mainly, the adult population of sub-Sahara Africa. Consequently, many children are becoming orphans with little or no prospects of a real future (UNICEF, 2003). Prevalence rates in the region continue to be the highest in the world (UNAIDS, 2006). As this number increases so does the number of orphans. Current indications are that by the year 2010, there will be at least twenty million children who will loose "at least one parent to HIV/AIDS" (Lewis, 2005); UNICEF projects this figure at fifty-three million (2006).

Zambia is reported to have one of the highest mortality rates due to HIV/AIDS, with projected life expectancy currently at age 40. As a result, the number of orphans also continues to increase dramatically. Zambia is also reported to have one of the highest numbers of orphans due to AIDS in sub-Saharan Africa, current estimates are at 710,000. (UNAIDS 2006).

The situation is worrying as more children are left to fend for themselves. Traditionally, as in many parts of Africa, orphaned children were usually absorbed into the families of their immediate relatives as a matter of course, when parents died. However, because of the extent and speed of the disease, families are no longer able to cope, as often, multiple members of one family group contract AIDS and die, at about the same time. The result is a growing number of children who end up living on the streets and having to survive on their own. A report published in South Africa indicates, that in 2001, there were about 10,000 children living and working on the streets in the country. (Gow and Desmond, 2002b). In several instances these children have to take on the responsibility of head of the house and, depending on their ages, have to look after and provide for younger siblings.

2.2 Issues affecting children
As a result of their parents' deaths, children are impacted in several ways including emotional well being, physical security, and mental and overall health. (UNICEF, 2004). Available literature seems to support this view. There is an overall negative impact that is experienced by these children, that unfortunately, because of high levels of poverty in this region, only seems to get worse.
Direct impact is usually physical with the children themselves becoming ill, and eventually dying. In many cases, poverty and inadequate resources, and support systems to provide nutrition, shelter and required medication exacerbate the high mortality rate among these orphaned children (UNICEF 2003). Even in instances where children have not contracted the HIV virus from their parent, these children are still at a high risk for illness including malnutrition and other childhood illness. (UNICEF 2003).

The traumatic effects of parental loss can have further negative psychological effect on behaviour, emotions and thoughts (Calhoun & Tedeschi, 1995). Children are equally prone to psychological distress and shock: first at seeing their parent's physical deterioration and helplessness and, eventually with experiencing their death (Gilborn et al, 2001; Ndongko, 1996). Psychological distress is expressed in varied ways. Some children take to living on the streets as a form of coping; depression is a common occurrence; various forms of juvenile crimes have been committed, including the abuse of substances (Gow and Desmond, 2002a). Children may become exposed to alcohol and drugs and use them as a way of shutting out painful effects (Calhoun & Tedeschi, 1995). Fear and anxiety about continuing livelihood and issues around security are common emotional reactions (Calhoun & Tedeschi, 1995). Children may continue to carry the effects of trauma long after their parents have died and, even when they have been settled in a new environment (UNAIDS, UNICEF, 2003). AIDS still continues to carry a stigma in many parts of Africa and is still associated with shame, fear and rejection. This is yet another psychological effect that these children have to endure. (UNICEF, 2003; UNAIDS 2000). There is evidence to suggest that children who lose their fathers due to AIDS become less depressed than those who lose their mothers. This has been attributed to the psychological nurturing that is believed to be provided by the mothers. (Basaza & Kaija, 2002).

Issues of economic survival also have an effect on children orphaned by HIV/AIDS. This is felt primarily through the absence of basic amenities, an inability to enjoy past activities and, in many cases, withdrawal from school (Ndongko, 1996). In a study on adjustment of orphans, Wild (2001) further states that children in some cases may end up losing their inheritance. In some instances, even those children who are able to continue with schooling do not perform well and eventually drop out. Reasons for this have been attributed to lack of parental guidance, poor nutrition and, absenteeism as a result of having to take care of their ill parents (Basaza & Kaija, 2002). An increased incidence of children having to become breadwinners or at least significant contributors to the family finances is not unusual. Children find themselves in a position where
they have to forfeit books and learning, with entering the job market (Jackson et al, 1999; Phiri & Webb, 2002). Because they are unskilled, children end up performing menial tasks that are usually harmful, requiring a lot of effort with minimal wages.

The economic impact can also be felt with respect to the health requirements of orphans. During the continued illness of a child's parents, available resources are normally diverted to obtain what nutritional requirements and medication is needed for the sick parent. More directly, it has also been found that children living with HIV-infected parents are more likely to contract opportunistic illnesses like Tuberculosis, malnutrition and stunting (Wild, 2001). As a result of their parent's illness, children can no longer obtain adequate levels of childcare and may not be able to even attend health facilities because their parents are unable to accompany them (Phiri & Webb, 2002; Gow and Desmond, 2002a). Once the parent dies, then even that slim source of funding is no longer available, making access to health care even more unattainable.

Children's opportunity to receive adequate nutrition is also affected; the amount and type of food that children receive is greatly compromised / reduced. A study conducted in Uganda in 2001 showed that orphaned children do not receive adequate food to eat, nor do they have a consistent diet. Older children especially were less likely to eat more than a few times in a week (Basaza & Kaija, 2002).

Overall the impact on a household where the main breadwinner dies due to HIV/AIDS produces a ripple effect. Family income is reduced and that sets off deficiencies in other aspects of the home (FHI, USAID, 2002). The amount of disposable income available to be spent is usually not adequate to meet the requirements of the remaining family members. As a result unavoidable sacrifices are made and far-reaching financial decisions are taken, that ultimately result in the family becoming poorer (Gow and Desmond, 2002b).

With Zambia reportedly having one of the highest numbers of orphans in the region, many children have become displaced because of unfavourable family circumstances and hence find themselves on the street. Several of them do not have access to inheritance that is rightfully theirs and see the streets as their only alternative (Phiri & Webb, 2002). The phenomenon of "property-grabbing" has increased the vulnerability and instability of children, as has homelessness (Gilborn et al, 2001). The streets however present other risks that these orphans have to face. Personal circumstances, such as lack of parental protection, and economic resources make these children
particularly vulnerable when they are on the streets. They are at risk for both mental and physical abuse, stigmatisation and perhaps most unfortunately they run the risk of contracting sexual diseases, including HIV. This is especially true when children are exploited for sex, in order to eke out some kind of living. Young girls especially who are in demand by sexual predators invariably get abused more so than boys (Phiri & Webb, 2002; UNICEF 2003).

The increased number of children orphaned by HIV/AIDS also represents an increased number of children who are working. The number of children between the ages of five to fourteen who are working in this region is estimated at about 29%. (UNICEF, UNAIDS 2003). At this age, many of these children do not have the physical capacity to perform optimally and invariably this has an effect on their physical development.

One other disturbing consequence, is that families and siblings often get separated after the death of one or both parents. It is still true in Africa that extended families continue to look after orphans; but unfortunately it is not always possible to absorb all the children from one nuclear family into an existing family. Hence siblings get ‘divided’ among the extended family and have to be raised in different homes. (UNAIDS/UNICEF, 2003). Studies in Uganda indicate that children find this separation particularly stressful as it leaves them feeling isolated. (UNAIDS/UNICEF, 2003).

Yet, notwithstanding the multiple negative effects that orphans, especially street children, experience as a consequence of HIV/AIDS many of them survive. They have continued to demonstrate resilience in their ability to look after themselves, to source food and in general to stay alive. It may be assumed that to some extent these children, as with most people, possess an inherent degree of resilience. The social support that they receive from their peers cannot be ignored in this case. Brannon and Feist (2000) speak about the positive link between good health and social support. If this is true then to some degree the same should be available to these children as they pass on and share survival skills; much in the same way that family and friends in society, in general, are seen to provide positive input to well being.

Although the literature indicates that the study of coping strategies in ordinary situations among children has received less attention than for adults, it has been acknowledged that most of the studies on children focused on specific coping strategies with respect to specific circumstances, e.g. Chronic illness. In general terms, coping strategies have been described as the cognitive and
behavioural efforts one makes to try to endure, escape or minimise the effects of stress (Lazarus, 1966; Lazarus and Folkman, 1984; as cited in Dumont & Provost, 1999). The theoretical viewpoint of McCubbin, Thompson, and McCubbin (1996) (as cited in Broome et al, 2004) also suggests that the coping mechanisms one uses are based on the resources that are available to the adolescent in their circumstances. Studies indicate that certain coping resources, both external (e.g. coping strategies, social support) and internal (e.g. temperament) have been identified (Sorensen, 1993). In the study conducted by FHI / USAID (2002) children who took part indicated several strategies or activities that they employed to deal with the pain of loss of their parents and the negative changes in their lives. Playing football, crying, visiting and playing with friends, praying and talking to someone were some of the strategies identified by the children.

The literature review has attempted to look at some of the issues that affect children orphaned by HIV/AIDS and some of consequences of their changed circumstances. There is limited information to indicate whether the same or similar issues obtain in Zambia; whether the orphans and vulnerable children in this study experience similar psychological issues around the trauma of changed life circumstances. The literature has also provided information on coping strategies and resilience, and what influences these attributes have amongst different individuals. Here again, there are limitations on available information. It is hoped that this work will add to existing literature currently available from Zambia.
3. Method
Qualitative research methods were employed as these were seen to best serve the aims of the study. Data collection was achieved through gender-specific focus group discussions. The decision to separate male and female was based on previous research and personal conversations with past researchers who had indicated that children often felt more at ease to discuss topics in groups when they were separated by gender. The focus group discussions centred around five central questions which are filed on Appendix C. The primary objective of the group discussions was to gain an understanding of the current environment from these children's perspective of how they have experienced the loss of their parents and parental illness, and how it has contributed to or taken away from their emotions and livelihood.

3.1 Participants
In order to obtain a stable and accessible population, research participants were sought from two established faith-based orphanages in Lusaka; these are the ‘City of Hope (COH)’, which is a girl’s orphanage and, ‘Jesus Cares Ministries (JCM)’ a boy’s orphanage. An equal number of males and females were purposively selected from between the ages of thirteen and sixteen, with sixteen participants in total. All the children in the study have lost both parents. The orphanage authorities assisted in the selection process based on the criteria already specified. Selection was also based on the requirement that the participants had been registered at the orphanage for at least six months and, that the children were in good health at the time of the study.

3.2 Procedure
Prior to the discussion, meetings were held with authorities at both orphanages. These meetings served to re-iterate the purpose and process of the research study and to make clarifications, where necessary. In both institutions, a co-ordinator was appointed to work with this researcher. The orphanage authorities identified potential participants based on the specified selection criteria. They subsequently spoke with the participants in their care, to obtain verbal consent and assess willingness and ability to take part. Once a final decision on participants was made, the authorities provided signed consent for each child, in their capacity as legal guardians. Separate meetings were then held between the participants and this researcher. The initial meeting was primarily for rapport building. The following was also achieved: the study and process was explained verbally and in writing; consent forms for participation and recording were signed; and questions were answered. The biographical questionnaires on Appendix A were then completed with the input of the institutions’ co-ordinator. All consent forms are filed on Appendix B.
The City of Hope (COH)
The COH is a privately funded orphanage and school that is run by the Catholic Salesian sisters. It is a spacious facility located in a quiet farming area of Lusaka. The focus group discussion was held at the COH premises in a classroom, where recording equipment had been installed. A song and the recital of a prayer preceded the discussion. Because the process had been explained to the girls in a previous meeting, the discussion proceeded immediately and was completed in a total of one and three quarter hours. The girls all spoke in English, although there was some limited use of vernacular. The general atmosphere was quite emotional, with many of the girls tearing up or crying during their own narratives, and those of the other participants. At the start, some of the girls showed anxiety about responding and therefore did not participate in the first two questions. As the discussion progressed, the response rate increased. A short debriefing session was held after the completion of the discussion. A follow-up session was held five days after the discussion took place.

Jesus Cares Ministries
JCM is a Christian ministry that is involved in religious outreach programs and charitable activities. The Mtendere centre, where the focus group discussion was held is a facility mainly for former street children who have become orphaned and/or separated from their families. As part of their program, JCM tries to reunite these children with their families where they are able. Because the facility is located in a township, near a busy road, some noise filtered through, affecting the flow of the discussion. The discussion was held in a staff room, and recording was via a hand-held recording device. The discussion was conducted mainly in two local languages, i.e. Bemba and Nyanja, both of which this researcher is fluent in. Some English was also spoken. The session was boisterous and often interspersed with nervous laughter, even when difficult issues were being discussed. A short debriefing session was held after the completion of the discussion. It transpired that counselling sessions are provided as needed by the children.

3.3 Limitations
At the start of the first focus group discussion, not all the girls took part in answering the first two questions, and so the response rate between girls and boys was not equal. (The response rate is indicated on the graphs). The emotional state of some of the girls also meant that participation was further limited.
It was also observed that the boys spoke ‘street slang’ and therefore did not access the rich vocabulary that the languages spoken offer. As a result, their expression of feelings, in particular was limited.
4. Results

4.1 General comment
Data analysis from the focus group discussions revealed that, for the most part, there is consistency across both groups. Differences noted relate specifically to the behaviour of the male participants, in the period between their parent’s demise and their integration into the orphanage. Through a process of refinement and reiteration, nine themes were identified, in response to the overall research questions. These are; negative socio-economic change, emotional suffering, social isolation, loss of family safety net, premature entry into adulthood, survival and coping, the role of external intervention, violation of child rights, and stability and the future.

4.2 Data analysis
Thematic content analysis was used to analyse the data. This researcher first transcribed the tape recordings from both sessions. A translation of the JCM recording into English was also done simultaneously. A walk-through was made, in order to verify the accuracy of the transcribed data. Data was then worked through inductively with the aim of detecting, grouping and classifying unique categories, and eventually themes. A continuing process of refinement of categories formed part of the categorisation, to ensure symmetry with the research questions and also to streamline the number and variety of categories and themes.

The first part of the categorisation coding process yielded an initial two hundred data segments. These were derived from participant responses to the focus group questions. For the purposes of maintaining a concise audit trail, the data segments were identified by topics, as illustrated in the example below. The topics identified through the focus group questions, are presented graphically at the end of this section on figures one to ten respectively.

1st level coding

Table 1 – Identification of topics from data segments

<table>
<thead>
<tr>
<th>Data segments - underlined</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1: For me what I have seen is that um, I don’t have… it has changed, it has changed because I don’t have anyone who I can run to, where to say ‘mum bring this for me, I want this and this, and I cannot… when my parents were there I was demanding anything that I want, but now I cant demand to anyone./And it has changed because this time I cannot demand, I’ve got no one who I can call mummy/, and I’ve got no-one who can make me feel, who can make me feel as if, I’m, I’m the daughter… So it has changed for me.</td>
<td>a. Being without no provider</td>
</tr>
<tr>
<td></td>
<td>b. Feeling abandoned</td>
</tr>
<tr>
<td></td>
<td>c. Being without mother/ love</td>
</tr>
</tbody>
</table>
Each data segment was used to illustrate a particular concept, experience or event for individual respondents. Once this process was complete, the data segments were reviewed, to identify similarities throughout the data. Topics with similar ideas or issues were then grouped together under a category and assigned a meaningful label, as follows.

Table 2 – Classification of topics into Categories.

<table>
<thead>
<tr>
<th>Topics</th>
<th>Category (label)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Without /bereft</td>
<td>Negative socioeconomic change</td>
</tr>
<tr>
<td>• No provider</td>
<td></td>
</tr>
<tr>
<td>• Abandoned/ Alone</td>
<td>Emotional Suffering</td>
</tr>
<tr>
<td>• Being without love/ without mother</td>
<td></td>
</tr>
</tbody>
</table>

2nd level coding

Second-level coding involved re-visiting the categories and topics in order to develop and identify the nine themes represented in the table below.

Table 3 – Final themes derived from thematic content analysis of both data texts.

<table>
<thead>
<tr>
<th>Topics</th>
<th>Category</th>
<th>Code</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Without /bereft (1) (148)</td>
<td>Negative socioeconomic change</td>
<td>NEC</td>
<td>1. Negative Socioeconomic change</td>
</tr>
<tr>
<td>• No provider (4) (4a) (8)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Changed living conditions: step-mother introduced brought difficulties (88) (110)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Family harmony disturbed – street became only option(89)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Negative change in living conditions: no amenities(92)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Ill-treatment; home comforts no longer available; insecurity(97)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• School disrupted(99)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Unbearable home life; no care/comfort(100)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Moved to extreme measures- stealing (101)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Enduring extreme hardship (102)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Homelessness – living on the streets(103)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Truancy(105)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Involvement in truant activity(106)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Abusive behaviour(109)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Substance abuse as a result of family break-up (114) (118)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Family’s inability to function(142)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Abandoned/ Alone (13) (29) (69) (75) (137)</td>
<td>Emotional Suffering</td>
<td>ES</td>
<td>2. Emotional Suffering</td>
</tr>
<tr>
<td>• Being without love/ without mother(3) (15) (121)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Topic</td>
<td>Social Isolation</td>
<td>Remembrance</td>
<td>Collapsed into FSN</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>------------------------</td>
<td>-------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Love lost/gone (6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disbelief(7)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life as difficult (16) (123)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No mother’s love(17)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling like nothing – worthless(19) (135) (138) (144)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Invisible, worthless, not human (20)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disconnected, not belonging(23)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alienated(24)</td>
<td></td>
<td></td>
<td></td>
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*Note: The numbers in brackets represent instances within the transcripts where the topic appears. Numbers correlate directly to the transcripts*
Figure 1 Responses to focus group question number 1, for City of Hope participants.

Figure 2 Responses to focus group question number 2, for City of Hope Participants
Q. 3. Memories - COH

Recalling parental advice:
Celebration of birth/Family Reminders:
People giving reminders:
Religious/physical reminders:
Stability/constant

Disconnected no memories
Feeling special/loved:
Divided/conflicted family:

87.5 response rate

Figure 3
Responses to focus group question number 3, for City of Hope Participants

Q.4. Survival & Coping - COH

Coping through imitation/habits
Coping:
Friends/community
Distraction techniques
Extended family taking on mother’s role
Religious org.-COH security/care
Avoid/Abandoned no family safety net
Coping deception
NGO/pgm. & family collaboration

100% Response rate

Figure 4
Responses to focus group question number 4, for City of Hope Participants
Figure 5
Responses to focus group question number 5, for City of Hope Participants

Figure 6
Responses to focus group question number 1, for Jesus Cares Ministries Participants
Q.2 Feelings - JCM

![Bar chart showing feelings and topics]

87.5% response rate

Figure 7
Responses to focus group question number 2, for Jesus Cares Ministries Participants

Q3. Memories - JCM

![Bar chart showing memories and topics]

100% response rate

Figure 8
Responses to focus group question number 3, for Jesus Cares Ministries Participants
Figure 9
Responses to focus group question number 4, for Jesus Cares Ministries Participants

Figure 10
Responses to focus group question number 5, for Jesus Cares Ministries Participants
5. Discussion
Some of the information included in these themes, was obtained during the initial contact sessions. The children spoke briefly about their lives and some experiences that they had, had since the loss of their parents. During these discussions, some of the children admitted to knowing that their parents had died of AIDS, while others said they suspected that was the case, because their parents had become very thin and been transferred to hospices.

As part of the analysis follow-up process, the identified themes were later verified with the participants in order to confirm that a correct understanding was made. On the return visit to JCM, it was found that three of the original participants had been rehabilitated with extended family members.

Information gathered from orphanage authorities has also been included. Some of the children’s responses are included in italics.

5.1 Themes

5.1.1 Negative socio-economic change
The socio-economic impact of HIV/AIDS is perhaps what is outwardly, most noticeable. As stated earlier, all the children who have participated in this study are living in orphanages. While they may be considered as the lucky ones, since they are in more stable environments at present, their lifestyles have changed significantly, since the loss of their parents. Further, the interim period between their parents death and entry into their current homes, has for the most part been challenging.

All the children experienced a disruption in their school attendance, either during their parent’s illness or after their parents’ subsequent deaths. Ailing parents were no longer able to make available necessary school provisions to enable their children attend school, hence most of the children had to leave school for some period of time. Foster and Williamson (2000), speak about this decision by parents for their children to discontinue school attendance. They attribute it to various reasons such as the reallocation of funds to pay for medical expenses; the need for older siblings to look after younger siblings at home while the parents are ailing or, to take over other household chores. This happens more frequently to girls than boys. UNICEF (2006) reports that this gender discrimination is because of a perception that girls are not equal to boys, hence the likelihood of their being exploited first. In Zambia, boys are at least ten percent more likely to
complete their education than girls are. (Fleischman, 2002). The parents inability to provide, was also felt in the absence of basic necessities such as food, adequate shelter, security, proper hygiene and so on.

\[
\text{What I have seen as having changed is that once when I was on the streets, I wasn’t sleeping – I was not sleeping in a good place; food was only available if you were able to find some small job; and there was no opportunity to bathe, you could only bathe very rarely and then not thoroughly...}
\]

\[
\text{...and that’s when you realise that all is not well here. So the laughter you had as a family, starts to change...you start to notice things change. Maybe even eating and how you eat becomes difficult, standards start to drop....Maybe you find that you have to go and ask others for food; your heart just starts to feel heavy / bad...and all that and you start to wish that your father would just get better...}
\]

\[
\text{Okay...you know its different when your parents are alive and well... that with everything you feel free, you enjoy life and all is good. Even eating is a pleasure. But once my parents died, everything became difficult, from going to school, eating and even enjoying life – everything was difficult...}
\]

The situation is further exacerbated by the issue of poverty. While none of the participants described themselves as poor, their stories suggested that the majority of them came from families that were not necessarily affluent. The scarcity of savings to cushion unemployment, the absence of medical insurance, and the lack of economic security are indicators that these families can only best be described as working-class. Hence when the main breadwinner becomes ill the phenomena of diminishing wealth arises; medical and other expenses increase, while the ability to generate income and the capacity to work, is decreased (UNICEF 2006). As a result of this increasing poverty, children could miss the opportunity for gaining an education and perhaps lose the chance to learn a trade. (UNICEF 2007; USAID, FHI 2003).

It was observed that without exception, all the boys spent some time living on the streets. The reasons put forward related to disruptions within their parental homes, change of living conditions and other lifestyle adjustments. According to a 2002 report produced jointly by some Zambian non-governmental organisations and Project Concern International, homelessness, increases the risk of such children to contracting illnesses such as HIV because they have no parental guidance, are exposed to potential sexual abuse, have little education, and may be forced by economic
factors to turn to selling sex as a means to survival (Fleischman, 2002). Some of the boys travelled long distances from their places of origin to the larger cities in search of a better standard of living. They all endured harsh living conditions on the streets where they often had to find menial, badly paid jobs in order to provide food for themselves. This researcher spent some time trying to understand what compelled the boys to leave home and the girls not to. While there is difficulty in leaving home, especially in the situations experienced by these boys, there are some who see it as potentially positive. Felsman (1981) (as cited in Panter-Brick and Smith, 2000) speaks about leaving home for the streets as possibly being “a positive, adaptive move towards physical and psychological health.” Children may rationalise that the streets present a ‘better’ environment free of disruption, ill-treatment and other negatives, and so they opt out of their homes, and take their chances on the streets. In reality, however, these boys continue to suffer economic hardships, exacerbated by no real means of support and an absence of parental guardianship.

5.1.2 Emotional suffering
The emotional impact of parental loss is still quite keenly felt, especially among the female participants who cried frequently during the discussion. In contrast to the boys, this researcher observed that feelings of extreme hurt and pain were evident in their body language; they shed tears repeatedly, wrung their hands often and spoke with emotion-filled voices. One of the girls spoke somewhat mechanically, almost as though she had separated herself from the pain that her recollections evoked. Throughout their narratives, participants repeatedly expressed feeling abandoned and unloved, feelings of being isolated, feeling unsafe, and being apprehensive without the security of their parents. Other difficult emotions that they spoke about were sadness and hurt, pain and disbelief and, feeling stigmatised. Janoff-Bulman and Berger (2000) speak about the loss of invulnerability which the children experience, as being a part of “the aftermath of extreme negative events”. The realisation that something so intense could happen to them leaves them feeling defenceless.

More than adults, children begin to rely on what they know; their homes, their families and their social networks, which they see as permanent and reliable. They form attachments which allow them to feel secure and give them the freedom to explore the world beyond from a stable base that they feel anchored to. Most children learn the inevitability of change when they are older and better able to deal with the implications, as they mature. These children however, did not get the
chance to learn about how life changes and develops through the cycle that humans have come to accept as normal. This unexpected loss of invulnerability may account for their extreme feelings.

As for me from the day when my mother, my parents passed away, I don’t see anyone to love me, as the way my mother usually used to love me, as my mother used to love me. And some times when I sit down, I can’t believe that my parents passed away.

...and I’ve got no-one who can make me feel, who can make me feel as if, I’m, I’m the daughter...

In a United Nations report on violence against children, Pinheiro (2006) reported that rejection, isolation, emotional indifference and so forth are perceived as forms of violence that can be harmful to the psychological development and well being of a child; this was especially true if the adult was respected by the child. It remains to be seen what, if any, lasting damage the children may suffer as a result of early parental loss. Perhaps one negative consequence for the girls, has been that, to date none of the high school leavers have achieved high academic standards. According to the Mother-superior, none of the children have progressed to tertiary education.

The effects of early childhood vulnerabilities, due to loss of their parents, could have a lasting impact on these children in later life (Raphael & Dobson, 2000), which is already compounded by their lack of academic achievement.

Some might argue that the child’s perception of abandonment and isolation does not necessarily reflect reality, nor does it represent the deliberate actions of the parents. However, some children understand their parent’s death and illness as turning away and leaving them to fend for themselves. The expectation is that sick parents, will get better; death is not an option. While on some level they can articulate that the death is not in fact deliberate and their parents are not at fault, they still experience it as negative. Notwithstanding the ‘facts’, it is the child’s expressed experience that is critical. Over time, as with most people, these children have learned to master their grief.

...When she died, it hurt a lot, because I thought that maybe she would get better, but she didn’t.

...The way I felt was while they were alive I was just happy and all was well; but when they began to get sick, my heart began to feel ‘hard’...
Several of the participants articulated their lack of connectedness to people that loved them, and this appeared to have had an impact on their perception of their own self worth. In this regard, a number of the children questioned their usefulness in the light of their parents’ death, expressing feelings of helplessness and being without hope. Foster & Williamson (2000) have observed that “Internalised behaviour changes such as depression, anxiety and low self-esteem” are more evident than externalised behaviours in children that are orphaned. This tendency to internalise may be due to their inability to find ways to express their grief adequately.

I did not feel good about what was happening, I just used to feel very bad… I cant find words for it… as though maybe I should not have been born to this earth, maybe God should not have made me. I used to ask myself, what purpose I had on this earth… especially with what was happening… perhaps I should not have been born….

The universally accepted cycle of life is that children expect their parents to be available to them as they grow into adulthood; and in doing so, that they will have guidance through the challenges of life. Additionally they see themselves as belonging to a supportive family unit that provides meaning in their lives. Unfortunately, these children’s narrative suggests that the loss of their parents has disrupted the natural flow of their lives, and left them without direction and significance. And so they question their worthiness in a world without parental protection.

... I feel so frustrated… I have even given up completely at times, not caring what happens to me… I feel so heart broken…

One participant communicated how low frustration tolerance had in the past, caused him to have dangerous thoughts. Another spoke about feeling as though there was nothing to live for.

When I was feeling that way, and someone said something, I sometimes felt as though I could hurt them so badly… sometimes maybe even kill them… I feel so frustrated… I have even given up completely at times, not caring what happens to me… I feel so heart broken…

It would seem that in many aspects of their lives, the children have begun to find ways of coping, however, it is with some difficulty that they are able to engage with their feelings. This is particularly difficult in the face of multiple family loses.
I don’t think much about my mother; because my brother died first, then my mother, and my father and lastly my younger brothers – twins. So I am the only one left in my family, from my mother’s side. So when people tease me about being an orphan, I don’t pay the any attention... after all they cannot hear the taunts and insults so it makes no difference. So I don’t really feel anything.

The environment they are in, and the well-meaning volunteers who are their current guardians, have done their best to provide the basic needs however, according to some, their efforts still fall short.

I think the sisters; the sisters have made me to survive, cos they are the ones who are keeping me. They give...cos they give me all those things which I need for example...although they cannot give me the love which my mother used to give me, but they are trying to give me all the love that I need.

5.1.3 Social isolation
The participants spoke about feeling cut-off from their familiar social contacts, believing that they were alone, without anyone to rely on. A number of the children talked about being left in the care of extended family members after their parent’s death. In some cases, the experiences reported were difficult; with participants often narrating incidences of negative treatment received in these homes. Results also indicated that children are facing rejection and being neglected by family members who previously showed them love and concern. Some of the children, who went to live with extended family, reported being subjected to ill-treatment from their guardians. In some instances these children felt that they were regarded differently from the other children in the new household. According to them unfair treatment and disciplinary measures were employed. On the issue of unfair treatment:

...after school they never allowed me time to read and study, because as soon as I had eaten they would send me back out to the fields to work. To the extent that during holiday time, they did not allow me to go on holiday, yet their children went.

One child spoke about instability, where she was shunted among relatives, for varying reasons until finally, she was institutionalised.

I remember when I was young, my mother, and also I remember when we were at school, we were staying ... with my mother. And then my mother passed away and then we went to the village where my grandmother used to live. And then I started living with my grandmother, and then my
grandmother became ill, and then she went to another village. And then I started living with my big brother, I had two big brother, and then afterwards I went to the best friend of my grandmother, that’s where we were staying. So the best friend of my grandmother was just good to us but not the grandfather...

Few of the children indicated a continuing positive relationship with their relatives. Traditionally, in Zambia the expectation is that the extended family steps in to care for children that become orphaned. This informal adoption, is a matter of course in most instances. However, the ever decreasing number of relatives who are able to fulfil this role, has resulted in this support system becoming more difficult to access. According to UNAIDS (2006), in Zambia, the HIV prevalence rate among adults aged between 15-49, is 17%, with mortality rates, estimated at about 96 000, per annum. Consequently, the number of adults who will be available to look after orphans will remain low, and children will continue to have the experience of being neglected and rejected by the very adults that they expect to protect them.

A supposed well-meaning effort to shield one child from the trauma of illness, only succeeded in having the opposite effect. One of the girls spoke about external interventions that sought to separate her and her sibling from their ailing mother. She was particularly hurt by these efforts as she felt that she could have helped nurse her mother through her illness, thereby maintain some connection with her before she died. She was left feeling excluded.

…but people from TASINTA, they didn’t want my mother to be coming to see us…I don’t know the reason why; then when my mum came, she was coming there to see us with my brother…she was coming there to plait me, bringing us some dresses, shoes. Then there’s a boss in TASISNTA program she came there and she told us that when your mother will come again, you should refuse, but me I wasn’t refusing….if my brother refuses, I will just go alone to my mother… Then I take care of my mother in the holiday…

It was found that the girls at COH felt further separated from the outside world as they reportedly had few, if any friends outside the confines of COH. While this may be because the institution is somewhat isolated, few of the girls spoke about having relationships with the non-resident children who attended the school on their premises. For the authorities too, there are constraints associated with trying to integrate/expose these children to the world outside their confines. Scarcity of funds, logistics, reliance on the charity of others, and so on, are some of the obstacles
that they have to negotiate. So it would seem that circumstances conspire to further isolate these children.

The Mother-Superior of the COH indicated that once the girls have completed their secondary school education, they often have nowhere to go and so some remain at the orphanage while others are set up in groups of three or four in housing sourced by the sisters and, assisted with finding jobs. She also said that society does not consider these girls as suitable marriage partners, thus adding to the stigma these girls already have to contend with as orphans. In their report on Enhanced protection for children affected by AIDS, UNICEF (2007), indicated that the label of orphan could act as a barrier for these children to access “financial assistance and block the approval, development, or implementation of protective legislation and policies increasing children’s risk of experiencing violence and abuse”. And so it would appear that orphan hood has condemned these children to a future with little hope.

5.1.4 Loss of family safety-net
Loss of family and what it represents has had a significant impact on the participants; most of the children made some reference to the changes experienced when they were no longer part of a connected family unit. The dislocations and deprivations that the children experienced meant that they have lost the familiar and can no longer access the protection that a family environment provides. As a result, many of these children were left without effective guidance and had to rely on their own limited competencies. Children begin to experience the effects of parental death from AIDS long before the actual death, and also long afterwards.(CARE, FHI, USAID, 2003). Social stigma, gradual impoverishment, and stress related to possible increased responsibility may start and progress during the illness. (UNICEF, 2006).

While the death of a parent is in itself difficult as it denies the child, among other things, the potential for being nurtured and protected by someone who loves them; it is however the subsequent life changes within the home that seem to have affected the children even more. When both parents die, children are unlikely to remain in their parental homes and may get split up among various relatives, thereby compounding their losses. They may be further denied access to other social networks such as school, friends and community,(Dane, 1997, as cited in Wild, 2000). The ‘sharing out’ of orphaned children is a strategy employed by extended family members, in order to divide the responsibility of care.(Foster & Williamson, 2000).
The absence of parents or a concerned primary caregiver in a child’s early years may impede the development of essential “mental processes and faculties”. (O’Hagan, 1993). A child may experience psychological difficulty if they are not able to adequately gain and retain an understanding about the world, acquire moral standards (Berk, 2000) and be able to find a place for themselves within the context of a functioning unit.

Bronfenbrenner’s ecological systems theory views the development of a child through a social context of relationships within multi-levels of the environment, on a give-and-take basis. (Berk, 2000, Pryor & Rodgers, 2001). At the micro- and meso-system levels a child interacts primarily within a nuclear family unit, and then later, within the immediate community of child-care, school, health professionals and community. Thus a child’s core well-being is governed by the quality and support provided within these interactions. At the macro-systems level, a child interacts within a wider community with culture, belief systems, attitudes and social policies. (Pryor & Rodgers, 2001). At this level, traditional extended family practices should have come into play for the children; unfortunately, they did not, and so the system failed them. The failure of these systems, has thus denied the children of potential social capital, and increased the probability of their suffering harmful negative consequences.

Some of the children in the study, experienced neglect from their own siblings, with some being made to go without basic necessities such as food. For the male participants specifically, changes in the nuclear family construction such as the introduction of a step-mother (which has been found to sometimes affect family cohesion), may have exerted some social pressure which caused a disruption in the domestic workings of the family that threatened their psychological adjustment, because of their dependency on the family’s smooth functioning. (Hauswald, 1987). Consequently, the family’s subsequent break-up resulted in all of them opting for a life on the streets. A majority of the female participants ended up in transit homes.

For me I remember that when I used to live with my mother, things were good...better. But at the time she died – you see my father had married a step-mother. So living with her was difficult and we differed often...you see she had her own children, so living was difficult. I remembered that when my mother was alive, things were not so hard, and now that she is gone everything is difficult. We started to have all sorts of different, little problems...so in the end I just went on the street... That’s how I found myself on the street. Because I never thought that I would even be living on the street, but I ended up there just because my mother had died.
Participants spoke with nostalgia about happy family lives, lived within functional family units. This was true even when they narrated stories about being disciplined for truancy and other childhood mischief. Recollections of lessons learnt, and advice given, were expressed as means by which they continue to keep alive the memories of their parents and to endure the challenges they continue to face.

...Then when it was my birthday, because my father had a car before he died, when it was my birthday, he took me for a ride. Sometimes he took me to the company; he gave me whatever I wanted, and when we went home in the afternoon, I found things on my bed. Then they baked for me a cake, we were celebrating, we were happy together with the family...

So, for these and many other vulnerable children, institutional care seems to be the safest option as it offers a relatively high degree of protection and structure. This is especially true where the traditional safety nets offered by extended family are becoming less accessible. However, past research on the institutionalisation of children has long found a number of challenges including issues related to child development and attachment; inadequate staffing levels; staff attrition; and the lack of auditable standards. As the children become adults and have to leave these residences, they continue to be at risk because of the stigma of growing up in these environments, and could therefore become repeat victims of society’s unwillingness to accept them.

5.1.5 Premature entry into adulthood
The issue of taking on the responsibility for younger siblings was a recurring theme. Older children were often tasked with the role of looking after other nuclear family members because the primary caregiver was no longer alive or able to fulfil this role. A gradual shift in responsibility begins to take place when parents start to get sick. A role-reversal may begin to occur where the traditional roles of caregiver and receiver are exchanged. In more extreme cases, older siblings become heads of household and become fully responsible for those left in the home. According to a UNICEF (2006) report, incidences of child-headed households are still relatively rare in Sub-Saharan Africa. During the discussions, it became apparent that the participants in this study were unprepared or unwilling to relinquish their childhoods to become caregivers themselves.

...Then what I don’t miss is someone telling me that, that you should, you should take care of yourself and your sister. This I don’t miss because my mother used to tell me many times, when
going to school take care of yourself and your sister...here Sr. M. always tells me take care of yourself and your sister; my grandparents take care of yourself and your sister; so this I don’t miss because its too much for me....

...my mother used to say to me, you see your father has died, and when I die, don’t follow or emulate men or your friends who tell you to go with them to drink alcohol, and do ‘stupid / irresponsible’ things...don’t do it...You should remain looking after your younger ones ...that is what I am encouraging you to do most of all. Because you will remain as the ‘father’ of your siblings to watch over what they will be doing.

The inevitability, in some cases, of having to take on adult roles when they have not been adequately equipped for them, could bring on resentment and anger towards ill or deceased parents. The perception of deliberate abandonment is further increased and may precipitate adverse psychological and emotional reactions such as depression. Furthermore, “such children many develop passive and compliant personalities as part of a pseudo-maturity which involves missing out crucial childhood developmental experiences”. (Dale et al, 1986, as cited in O’Hagan, 1993). Their inability to cope in the adult world could leave children with “lower expectations about the future” (Foster & Williamson, 2000). And so these children will enter the labour force at a low level, with inadequate wages, and ultimately it becomes possible that a cycle of poverty is perpetuated. The situation further places these children at an increased risk for exploitation and abuse.

The potential for early marriage and unplanned pregnancy were also raised as risk factors in the girls’ discussion. One girl spoke about being protected from early motherhood by a considerate family member, while another voiced her concern of extended family members who expected her to get married after her mother had died.

...So me when my both parents passed away, ... there is no-one who can say ‘hello baby’, what, what, telling you those things, they only ask me about when are you going to get married those questions...so it changes...

While both boys and girls are at risk of sexual abuse, in Zambia, girls still continue to be at the greater risk, and as such, at a higher risk for HIV infection. According to Kielland and Tovo (2006), Southern African girls between the ages of 15-19 have six times the infection rate of boys the same age. Further, research evidence shows that children who live with extended family
members are at a higher risk for sexual abuse by family members such as uncles, stepfathers and cousins. (Pinheiro, 2006). For a long time, embarrassment and the fear of recriminations has ensured that these abused children (especially girls) remain silent. Unfortunately even relatives who are aware of this abuse taking place are often complicit in maintaining this silence. And so, it would seem that the environmental and social risk factors increase for children who are not ready for, but are forced into adulthood.

5.1.6 Violation of child rights
The violation of child rights though not spoken about as much as perhaps other concepts, still represents an important aspect of the lives of these orphaned and vulnerable children. This is especially true for the boys who ended up living on the streets. Homelessness denied the boys the security that a home provides against social and environmental threats, and resulted in them losing the psychological and social comforts that a home would normally offer. (Morse, 2000). While none of the girls in this study had to endure life on the streets, it should be noted here, that this does occur, and girls are often seen to be more at risk from sexual predators than their male counterparts.

In order to survive the suffering that ensued from their destitution, the boys often had to engage in difficult, sometimes dangerous jobs just to make enough money to buy food to eat. As a consequence of their vulnerable position they were often exploited by adults and made to do more work for less pay. Understanding the extent of child labour in Africa is somewhat complex. The International Labour Organisation (ILO) has set out specific definitions on the basis of age and type of work or economic activity that children engage in. ILO convention number 138, states that between the ages of 13-15, children may engage in light work. The extent to which the work negatively affects the child’s health, security and morals is a critical consideration. (Kielland and Fong, 2005).

Unfortunately the phenomena of child labour in Zambia, as in other developing countries, is not new nor is it necessarily perceived as unacceptable. In 2005, Sub-Sahara Africa had approximately forty-eight million working children under the age of fourteen, most of them in an unregulated, illegal informal sector. (ILO, 2005). Traditionally, children’s involvement in economic activity, especially in rural communities, was based on customary practices where the work of children was age appropriate and designed primary as a learning tool, and as part of the
child’s community engagement. This was seen as part of “shared domestic management and family social support” (Weisner, 2001). Over time, and due to industrialisation, rural to urban migration, poverty and so on, the type of work that children engage in has become inappropriate and exploitative in many instances. The work that children now do is more about economic survival, and possible exploitation, than cultural participation.

The boys spoke about fetching water in large drums, ferrying goods on wheelbarrows (often too heavy for them to move), sorting through charcoal and breaking boulders to make small stones at quarries. This work was often backbreaking and harmful to the children as it affected their physical and mental health and, natural development. However the boys still made attempts to perform these jobs as they were not in a position to choose.

*When the money was all spent, we started to wonder how we would survive. We decided to take my father’s old wheel barrow and start a small business. We would use it to carry people’s parcels for them in the city centre. The business did not go well as we were too small to ferry around the large parcels that people had.*

The boys also reportedly suffered at the hands of their families and extended families who they said mistreated and abused them.

*For me when my father eventually died, my elder sisters began to act as though the house was theirs. So things got worse and worse, they were not treating me as my parents used to treat me so we never got on very well. I did not eat or sleep properly and I was not free. So I went onto the streets where life was a bit free but also very difficult.*

The reality of adoption, especially in the economic circumstances of many of these families is that, just one extra mouth to feed represents a significant increase in the financial outlay of the guardians. Often, the adoption is less about being voluntary and more about a sense of obligation. However, it is the opinion of this researcher that, in line with cultural practice, extended families would like to help, but, they find themselves reluctant to do so because of the increased financial burden it places on their already stretched resources. Kielland and Tovo (2006, p. 46), report that in some southern African countries orphans are often taken in by relatives for “…commercial gain, either from their labour or for grants made available to orphan caregivers…” Girls especially, are utilised as domestic help, and are thus more likely to be taken in by relatives: this may explain why the numbers of girls on the street is less than the number of boys. It also puts
them at increased risk for potential abuse by male relatives. Thus children who already have to endure orphanhood, continue to be exploited at the hands of those who should be helping them.

5.1.7 Survival and Coping

This marked the main point of departure between the boys and girls in the study; there was a clear distinction between how the two groups found ways to cope. The experiences of these children, has placed them in special communities of people who have had similar experiences to their own; this in itself has been positive. Research supports the understanding that difficult life circumstances and events, are known to bring people with similar experiences together in supportive social networks (Janoff-Bulman & Berger, 2000) notwithstanding whether its is perceived as positive or not.

The girls articulated what are often described as healthy coping techniques that they have employed to deal with the loss of their parents. These included interaction within their community of friends; distraction techniques such as reading, listening to music, singing and so forth. Also, recalling the actions and habits of their parents, and in some case, imitating them has been found to be useful by some. The old adage ‘a problem shared is a problem halved’ seems to hold true for the girls in the study. While institutional living has often been criticised because of a myriad of problems, it has got its merits and the girls have recognised it as crucial to their survival. Having had similar experiences of loss has allowed the girls to access people who understand and can relate to the difficulties that they have passed through. The importance of this support structure has been alluded to earlier in the literature.

I don’t, I don’t like being alone and thinking about what I’ve gone through, I like being with friends. So when each one is telling stories, I don’t think about them very much. Yes, when I sit down, okay I don’t usually have that time to sit and start thinking about them. All what I have is that when I’m alone, it could be I’m reading a novel, or I’m studying, or ifs its not that I’m alone, I’d better, I like listening to music a lot, I listen to music or I sit with my friends just talking.

In the case of the boys, they all lived through the community of street life and what that has entailed in terms of shared experience. Their coping strategies while primarily unhealthy and dangerous allowed them to exist from day-to-day. They admitted to taking alcohol and other substances while they lived on the streets. For the most part, it did not appear as though they abused substances merely for the fun of it, but in many cases, they saw it as providing some
protection against the harshness they endured. Some of the boys spoke about being able to sleep without feeling the cold, others used it to stave off hunger and yet others that it allowed them some respite from thinking about their situations. Bad behaviour and dishonesty as a means to coping came about as a consequence of substance use and hunger.

When I was on the street what helped me to survive was bostik (glue)…. Because on the street I used to feel very cold...so I would try very hard to find work so that I could make K2000, so that I could buy a tube of glue to smoke so I would start to feel better and warmer. When I slept I would do so with no problem until the next morning. Also food... I would go into the town centre, find a job and buy some food.

...From the beginning we used to smoke a chemical mixed with faeces(Jenchem), not this stuff they call TIK. So when you smoked you had the illusion that the ground was raising u ...There came a time when I had two bottles of this substance, I smoked a lot of it...we used to sleep very (dangerously) close to a fire...it was such that when u smoked this substance you were able to sleep soundly till the next morning.

In their current environment, the boys have adapted to healthier coping strategies similar to those employed by the girls. They also now have an active football team.

Notwithstanding the feeling of security that these institutions offer, it is important to acknowledge the personal resilience that each one of these children has. The ability of the children in the study to withstand the experiences that they have endured, may support the theory put forward by Cowen & Work, 1988 (as cited in Rhodes & Hoey, 1994) that possibly there exists a personality predisposition in resilient children. Not all children survive and thrive in institutions. One of the boys had been at JCM previously, but had run away and returned for a second time. Personal resilience has been attributed to various characteristics including self-sufficiency, sensitivity and having a sense of adventure.(Rhodes & Hoey, 1994).

Despite the methods used to cope with their individual experiences, the children continue to survive.
5.1.8 The role of external intervention

The resources of family and community support structures have been tested and become stretched due to what is seen by many as a crisis in Africa. Inadequate food security, land issues, public health, poverty, HIV and Malaria are some of the major contributors to this uncertainty. (Weisner, 2001). Reliance on community security structures, is slowly becoming a thing of the past; thus those most at risk such as vulnerable children have to look to other sources for help.

Perhaps the greatest contributor to the survival of the participants has been the intervention of faith-based organisations and well-meaning individuals. The absence of an effective social security system, has placed the responsibility of caring for orphans and vulnerable children largely, on the shoulders of the private sector. Most people in the developing countries of sub-Saharan Africa have no social security protection, and in places where this does exist, it is inadequate and does not meet requirements. Current estimates are at between 10-15 percent of the work force. (ILO, 2003). While social security is a human right, fewer than half of the world’s population has access to any protection. (ILO, 2003).

Both JCM and COH have nurtured the children and provided basic needs such as food, shelter, education, structure and security. They have also given the participants the opportunity to attain their fullest potential as well as provided religious instruction. At present, it would seem that the children’s future is secure: these are the lucky ones.

For me, what I found that is good, is that the way that my mother used to look after me, is the same way that I am looked after here...it's the same thing...because they help us to go to school, they help us with many things. The don't want us to become spoiled by the streets, they want us to be able to help others in the future; so we can show them too, what life is like....That what I have found...that what I used to be taught before (at home), I have found here too. So I would just like to thank those that look after us.

... the sisters have made me to survive, cos they are the ones who are keeping me. They give, cos they give me all those things which I need for example. Although they cannot give me the love which my mother used to give me, but they are trying to give me all the love that I need....

The HIV/AIDS epidemic has given rise to many private residential care facilities that are largely unregulated and in many cases unregistered. Zambian government estimates, place the figure of children in residential care at approximately 5000 (UNICEF, 2006). This is a relatively small
number, when compared to the number of orphans. However, the economic constraints that affect the majority of the population is making it more difficult for extended families to continue the practise of absorbing orphans into their families, hence this number will continue to rise. The same economic difficulties are affecting residential care facilities. At present, most are privately financed, and rely primarily on donor funding. Because of the increasing number of facilities being opened, and the lack of oversight by a regulatory body, donors have begun to require strict audit trails to determine usage of donated funds. These more stringent donor-aid requirements, while providing better accountability, may make it difficult for less efficient facilities to remain open.

On a wider scale, multi-nationals such as The World Bank Global Fund and UN agencies in conjunction with the Zambian government and the private sector are involved with reducing and arresting the spread of HIV/AIDS. The formation of a National Aids Council in 2002 resulted from the need to centralise and co-ordinate such efforts around the country. A recent USAID (2007) report, indicates that while mortalities continue to increase, new cases have begun to fall off, as risky sexual behaviours have declined. Awareness and education campaigns mounted largely by NGO’s and the private sector appear to have been well received and absorbed by many Zambians, and the results are slowly beginning to show.

The reality is that while public programs are making some headway, the pace is slow and will take some time to have any significant effect. In the meantime, Zambia’s many faith-based organisations are continuing their commitment to helping OVCs, by providing basic necessities.

5.1.9 Stability and the future
The current environment and the positive experiences that the children are encountering are allowing them to envision a future for themselves. The children feel that there is a real possibility that they can complete their education and become self-reliant. This, along with the presence of God in their lives, a stable and safe environment which is being provided by their guardians, have been identified as being uppermost in their current ability to survive.

On my side, it was really quite difficult…. Because I am praying to God that I am here, and I am also grateful to JCM…if it wasn’t for God, I would not be here.
While education, spiritual direction and constancy have been singled out as important, there is another element that has been voiced almost unanimously. The children’s individual life experiences and the actions of well-wishers have left them wanting to ‘pay it forward’ through assisting others, as soon as they are able.

... I want when I grow up, when I finish school, I should start helping other people...so what I am supposed to do here is concentrate and to follow what the bible says.

The difficult life experiences that the children have had, and the fact that they are alive with the possibility of successful futures, puts them among the survivors; and the children are cognisant of this. They have come to an understanding that while the world may continue to present them with obstacles, they have developed personal strength and are therefore equal to the challenge; their own stories give testament to this. In the light of this knowledge, the children in the study have all expressed their desire to help others who’s lives may mirror theirs.

I want to become a doctor, a medical doctor in life... I want to be a good citizen of Zambia, even to help other children, yes, as others have done for me. So I am very grateful to Jesus cares ministries, what they have done for me. Because I have a hope in life

At this stage, rather than viewing their lives as meaningless, they have begun to see the greater benefits of life pursuant to their own ordeals. In expressing their wish to help others, the children have shifted from being victims of parental loss to become survivors, and thus are able to view the positive side of trauma. The trauma of loss has allowed the children to “increase the value of particular aspects of their lives” (Janoff-Bulman & Berger, 2000) by wanting to care for others. And so, they are able to create value, rather than live with the negative aspects of their pasts.

Me for the thing which I can have which can make me feel better is complete my education and to have a good job in life. And my plan for the future is I want to, when I finish everything, when I will settle down, and when I stay well and succeed in life, I want to help the children of my sisters; the 1st born and the 2nd born and even want to reward the Sisters for the things they have done. Because without them I couldn’t even know English, or I couldn’t even know anything that I know by now. So my wish for the future is to help my family and to give a reward to the sister, and also help others who are in need of many things.
“As for me, I will just go on to be...what...the...to be trained here, to concentrate, because I want to be a lawyer also. As he has said that he wants to be a lawyer, I also want to be a lawyer. I want when I grow up, when I finish school, I should start helping other people...so what I am supposed to do here is concentrate and to follow what the bible says”.

The children realise that they have to be active participants in order to secure their future.

5.2 Conclusion

The issues raised in this study are in line with those identified in the literature review. Children whose lives are affected by HIV/AIDS through the death of their parents suffer the consequences at emotional and economic levels.

Previous studies have focused on the socioeconomic impact of HIV/AIDS on children, and there is evidence to suggest that efforts have been made to begin to address the immediate basic needs of a number of orphans and vulnerable children in Zambia. The economic climate in Zambia has continued to affect people’s ability to perform the obligations that have long been a part of the culture of caring for family, and so fewer orphans will find stable homes among their extended families. This being the case, facilities such as those included in the study may have to re-double their efforts to contain the growing numbers of orphans.

On an emotional level, children have been affected in several ways; primary among these is feelings of isolation, abandonment, hurt and pain. Forced entry into an adult world for which they are ILL equipped has also had a significant impact.

A number of aid, non-governmental, and faith-based organisation, have performed extensive studies to try to understand the emotional needs of orphaned children, in general however the literature does not evidence the amount of work done as a result of their findings. Perhaps because of the overwhelming number of OVCs, the task of providing assistance will, for some time, continue to be focused on basic needs. However as shown in this study, emotional needs can not be left unattended, as they can have adverse long-term effects on children’s behaviour, well-being and eventual entry into the world as adults.

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6. References


Berg, B.L., (2004). *Qualitative research methods: for the social sciences (5th Ed.).* USA: Allyn & Bacon


### 7. Appendix

**Appendix A – Sample Biographical questionnaire**

The following information was obtained from each participant.

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1. Identification number (to be assigned by researcher).</td>
<td>____________________</td>
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<tr>
<td>2. Date of birth</td>
<td>/ /</td>
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<tr>
<td>3. Are your parents still alive? (If the answer to this is no, then skip to No. 4)</td>
<td>Yes _____ No ______</td>
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<tr>
<td>4. When did your parent(s) pass away?</td>
<td>Year: ________</td>
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<tr>
<td>5. How old were you when they passed away?</td>
<td>Age: ________</td>
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</table>
| 6. How many brothers and sisters do you have? | Brothers: ________  
Sisters: ________ |
| 7. Are you and your brothers and sisters living together? | Yes _____ No ______ |
| 8. If not, where are they and who looks after them? | ____________________  
_________________________  
_________________________  
_________________________ |
| 9. Are you in touch with your family? (E.G. Extended family members). | Yes _____ No ______ |
| 10. When did you come to the orphanage? | ________ |
| 11. Where and who did you live with after your parent(s) passed away? | ____________________  
_________________________  
_________________________ |
| 12. Are you still in school? If not when / why did you stop, and in what grade? | Yes _____ No ______  
Year: ________  
_________________________  
_________________________ |

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Appendix B – Sample Consent Forms/ Information sheet

INFORMED CONSENT SHEET

Dear Parent / Guardian,

My name is Patricia Lumbi and I am a student at the University of the Witwatersrand (WITS) in Johannesburg, South Africa, where I am currently pursuing a master's degree in clinical psychology. As part of the academic program, I am required to conduct research. I would like to learn about how children are coping with HIV/AIDS, especially those children whose parents are deceased or whose parents can no longer care for them. I would like permission from you as the parent/guardian, to include your child in this study.

The child will be required to complete a form with the assistance of the researcher, which will tell me a little about the child and who is caring for him/her. He/she will also be requested to take part in a group session with other children. These sessions will be audio taped and hence your permission for this, is also required.

Participation will be voluntary, no child will be forced to participate, and they may withdraw at any time from the study. All personal information obtained will be kept confidential and be used only for the purposes of this study. The research data will be destroyed after it has been analysed.

We realise that some of the information that these children will reveal will be of a sensitive nature and may bring up feelings of pain and loss. With this in mind, the researcher will make every effort to ensure that sufficient psychological counselling help be made available to the participants, when any such need arises as a result of taking part in the study.

It is envisaged that the results of this study may further advance the understanding of the experiences of children affected by HIV/AIDS. It is also hoped that those involved in providing assistance and initiating support programmes for vulnerable children may be informed by the study's results.

Thank-you

_________________________   __________________________   __________________________
P. C. Lumbi Date:    Dr. M. Kasese-Hara Date:
Researcher     Supervisor
CHILD PARTICIPANT INFORMATION SHEET

Dear ____________.

My name is Patricia Lumbi, and I am here to find out about you and children like yourselves who may have been orphaned. I am currently studying at the University of the Witwatersrand in South Africa. I would like to talk to you about how you live, what you have gone through and how your lives have changed since your parents / guardians became sick and in some cases have passed away. The process will involve you and some of your friends talking and answering some questions that will be put to you. I will be present during these discussions, and the discussions will be tape-recorded.

I will need your permission, in writing on the form provided, if you wish to take part in the discussions. I will also need your permission to use a tape recorder.

I am hoping that the information you give me may help those who read my report to understand the experiences of children such as yourselves. It is also my wish that people involved in providing assistance and initiating support programmes for orphans and vulnerable children may find the information useful.

You do not have to take part, if you do not want to. Also you can withdraw from the study at any time. I will try to make sure that all the information that you give me about yourselves, is kept secret and will be used only for the purposes of this study. Since you will be having a discussion with your friends from the orphanage, it is important that you agree to keep what is discussed a secret and not to talk about it outside the group of people who are taking part.

If you start to feel uncomfortable or sad during the process, there will be someone here to help you. Do you have any questions?

Thank-you

__________ ________________ ____________ ____________ 
P. C. Lumbi Date: Dr. M. Kasese-Hara Date: 
Researcher Supervisor
PARTICIPANT CONSENT FORM

LEGAL GUARDIAN

I have read and understand the information provided above about the study and the process involved. I, being the parent / legal guardian, hereby give my consent for the child named below to be included in the study. I understand that the child will also be given the choice as to whether to take part in the study or not.

I ________________________________ ______________________________

Signature: Parent / Legal Guardian Date:

____________________________

Name of child ____________________

____________________________

P.C. Lumbi Date:
PARTICIPANT ASSENT FORM

CHILD

I have read and understand the information provided above about the study and the process involved. I agree to take part in the study.

Name __________________________

I __________________________________________  ______________

Signature:                               Date:

________________________

P.C. Lumbi                               Date:
CONSENT FORM FOR USE OF AUDIO TAPE
LEGAL GUARDIAN

I have read and understand the information provided about the study and the process involved. I, being the parent / legal guardian, of the child named below, hereby give my consent to have the focus group discussion audio tape recorded. I understand that the information on the audio tape will be kept confidential and will be used by Ms. Lumbi only for the purposes of this study. I understand that the recordings will be kept in a safe place and will be destroyed once Ms. Lumbi has completed her studies in the next two to three years.

I __________________________________________  ______________
Signature: Parent / Legal Guardian  Date:

Name of child ______________________

____________________________
P.C. Lumbi  Date:
CONSENT FORM FOR USE OF AUDIO TAPE

PARTICIPANT

I have read and understand the information provided above about the study and the process involved. I, being the child named below, hereby give my consent to have focus group discussion audio tape recorded. I understand that the information on the audio tape will be kept confidential and will be used by Ms. Lumbi only for the purposes of this study. I understand that the recordings will be kept in a safe place and will be destroyed once Ms. Lumbi has completed her studies in the next two to three years.

Name ______________________________

I __________________________________________  ______________

Signature:                               Date:

________________________________________  _____________

P.C. Lumbi                               Date:
Appendix C – Focus Group Questions

Questions for the focus group discussions

1. Please tell us about the changes that have occurred in your life since your parent (mother, father) became ill or passed away.
   - What daily activities in your life have changed and how?
   - How long ago did your parents pass away and how has your life been, in general, since then? Talk about your experiences.

2. For those of you that have lost a parent(s), could you please talk about how this has made you feel?
   - How did you feel when you saw your parents getting more sick?
   - Were you involved in caring for your parents when they were ill? What did you do?
   - What was the experience of caring like for you? How did you cope with these new responsibilities?

3. What do you remember / miss most about having your parents and living together as a family?
   - Is there anything that you don’t miss or is it better now?
   - What do you remember about your parents?
   - Do you have anything to remind you about them? What is it and how does it make you feel when you see it?

4. Please talk about how you have managed to survive without your parents to look after you.
   - What have you done, or what could you do to make yourself feel better?
   - What sorts of things do you do when you feel sad and lonely?
   - How have other people helped you to deal with the feelings that you experience?

5. What do you think would make your better now?
   - Do you have plans for the future?
   - What would you like to see happen in your life now?