

**EMPOWERING GRANDPARENTS WHO FULFIL THE ROLE OF PARENTS IN THE
CONTEXT OF THE HIV/AIDS PANDEMIC: A PSYCHO-EDUCATIONAL PERSPECTIVE**

By

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I declare that *EMPOWERING GRANDPARENTS WHO FULFIL THE ROLE OF PARENTS IN THE CONTEXT OF THE HIV/AIDS PANDEMIC: A PSYCHO-EDUCATIONAL PERSPECTIVE* is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.



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ABSTRACT

This study firstly investigates the prevalence of HIV/AIDS and the resulting deaths from an international, African and South African perspective. These statistics provide a backdrop to the phenomenon of grandparent-headed households. The needs of orphans and the characteristics of grandparent-headed households are explained. The researcher describes the services offered to these households by a number of supporting agencies internationally and in South Africa. Erik Erikson's model of psychosocial development is used as a structure to explain childhood grieving during the various psychosocial development stages, including adolescence. The views and experiences of a number of South African grandparent-headed households are described as well as the views of stakeholders offering support to these families. Lastly the researcher offers guidelines to professionals and lay people who endeavour to empower grandparents who fulfil the role of parents in the context of the HIV/AIDS pandemic.

CONTENTS

CHAPTER 1: INTRODUCTORY OVERVIEW

1.1	GENERAL AWARENESS	10
1.2	ACTUALITY OF THE PROBLEM.....	10
1.3	PRELIMINARY LITERATURE INVESTIGATION.....	12
1.3.1	International perspective	12
1.3.2	African perspective	13
1.3.3	South African perspective.....	14
1.4	PROBLEM STATEMENT	16
1.4.1	Sub-problems	17
1.5	RESEARCH AIMS.....	17
1.6	LITERATURE REVIEW.....	18
1.7	RESEARCH DESIGN	18
1.7.1	Demarcation	19
1.7.2	Selection of respondents	19
1.7.3	Data collection	21
1.7.3.1	Data collection for focus groups.....	21
1.7.3.2	Data collection for case studies	21
1.7.4	Data analysis.....	22
1.7.4.1	Data analysis for focus groups.....	22
1.7.4.2	Data analysis for case studies.....	23
1.8	VALIDITY AND RELIABILITY.....	24
1.9	ETHICAL CONSIDERATIONS	25
1.10	STUDY PROGRAMME	25
1.11	CONCLUSION	26

CHAPTER 2: LITERATURE STUDY

2.1	INTRODUCTION.....	27
2.2	PREVALENCE OF HIV/AIDS	27
2.2.1	Global HIV/AIDS estimates	27
2.2.2	HIV/AIDS in Africa.....	29
2.2.3	HIV/AIDS in South Africa	30

2.3	PREVALENCE OF GRANDPARENT-HEADED HOUSEHOLDS	33
2.4	NEEDS OF ORPHANED CHILDREN.....	35
2.4.1	Physical needs.....	35
2.4.2	Educational needs.....	36
2.4.3	Psychosocial needs.....	43
2.4.4	The needs of orphaned adolescents	47
2.5	CHARACTERISTICS OF GRANDPARENT-HEADED HOUSEHOLDS	49
2.5.1	United States of America	50
2.5.2	Australia	52
2.5.3	Sub-Saharan Africa.....	53
2.6	PREVALENCE OF ORGANISATIONS LENDING SUPPORT TO GRANDPARENT-HEADED HOUSEHOLDS	58
2.7	CONCLUSION	62

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

3.1	INTRODUCTION	63
3.2	FOCUS GROUPS	65
3.2.1	Motivation for the use of a focus group interview	65
3.2.2	Data collection.....	66
3.2.3	Data analysis.....	67
3.2.4	Selection of respondents for the focus groups.....	72
3.2.4.1	Grandmothers caring for orphaned grandchildren group	72
3.2.4.2	Stakeholders group.....	72
3.2.4.3	Orphans from grandparent-headed households group	72
3.3	CASE STUDIES	73
3.3.1	How to undertake case study research	73
3.3.2	Types of case study	74
3.3.3	Choice of a case study method for the present study.....	74
3.3.4	Selection of respondents for the two family case studies	75
3.3.5	Selection of the data gathering method for the case studies.....	75
3.3.5.1	Interviews	75
3.3.5.2	Motivation for the use of a semi structured interview	76
3.3.5.3	Data collection.....	77

3.3.5.4	Data analysis.....	79
3.4	CONCLUSION.....	80

CHAPTER 4: INTERPRETATION OF RESEARCH FINDINGS

4.1	INTRODUCTION.....	81
4.2	FOCUS GROUPS.....	81
4.2.1	Grandmothers caring for orphaned grandchildren group.....	81
4.2.1.1	Biographical profile of grandmothers.....	81
4.2.1.2	Precipitating factors to grandmothers becoming guardians to their grandchildren.....	81
4.2.1.3	Self-reported health status.....	82
4.2.1.4	Self-reported emotional status.....	82
4.2.1.5	Sources of income.....	83
4.2.1.6	Actual living expenses.....	83
4.2.1.7	Financial coping strategy.....	83
4.2.1.8	Supporting grandchildren with school work.....	83
4.2.1.9	Grandmothers' major difficulties.....	84
4.2.1.10	Speaking to grandchildren about sex and HIV/AIDS.....	84
4.2.1.11	Support received to date.....	85
4.2.1.12	Suggestions to organisations wanting to support grandparent-headed households.....	85
4.2.1.13	Source of grandmothers' resilience.....	86
4.2.1.14	Synthesis and conclusion of focus group.....	86
4.2.2	Stakeholders group.....	87
4.2.2.1	Involvement with grandparent-headed households.....	87
4.2.2.2	Profile of grandparents caring for their orphaned grandchildren.....	90
4.2.2.3	Ways in which grandparents access services of supporting agency.....	91
4.2.2.4	Needs of grandparent-headed households that supporting agencies are presently unable to meet.....	91
4.2.2.5	Qualities necessary for personnel working directly with grandparent-headed households.....	92
4.2.2.6	Lessons learnt to date with regard to supporting grandparent-headed households.....	93
4.2.2.7	Recommendations to agencies contemplating offering this type of service.....	94
4.2.2.8	Support needed by agencies.....	94

4.2.2.9	Synthesis and conclusion of focus group	94
4.2.3	Orphans group	95
4.2.3.1	Biographical profile of orphans	95
4.2.3.2	Living conditions.....	96
4.2.3.3	Aspects of life with their own parents they longed for the most.....	97
4.2.3.4	Counselling and emotional support received subsequent to parents' death	97
4.2.3.5	Appreciation of grandparent caregivers.....	98
4.2.3.6	Challenges with regard to being raised by elderly grandparents	99
4.2.3.7	Support offered by orphans to their grandparents	99
4.2.3.8	Areas in which orphans felt they could do more for their grandparent	100
4.2.3.9	Orphans' perception of elderly caregivers' greatest challenges.....	101
4.2.3.10	Orphans' views regarding the assistance that grandparents require from supporting agencies	101
4.2.3.11	Orphans' unmet needs which supporting agencies should consider	101
4.2.3.12	Synthesis and conclusion of focus group	102
4.2.4	Summary of all three focus groups	102
4.3	CASE STUDIES	103
4.3.1	Case study one: Grandmothers Against Poverty and Aids (G.A.P.A).....	103
4.3.1.1	Genesis of the organisation.....	103
4.3.1.2	Involvement with grandparent-headed households.....	103
4.3.1.3	Profile of grandparents involved in the programme	104
4.3.1.4	Grandparents' greatest challenges	104
4.3.1.5	Successes	105
4.3.1.6	Limitations	106
4.3.1.7	Needs of orphaned grandchildren.....	106
4.3.1.8	Qualities needed to do this work effectively.....	107
4.3.1.9	Recommendations to agencies contemplating offering this type of service.....	107
4.3.1.10	Needs of organisation.....	108
4.3.1.11	Synthesis and conclusion of interview: case study one.....	108
4.3.2	Case study two: Mama Sophie's family	109
4.3.2.1	Biographical profile of Mama Sophie's family	109
4.3.2.2	Living conditions.....	109
4.3.2.3	Financial situation.....	110
4.3.2.4	Health status of grandparent	110

4.3.2.5	Positive aspects to caring for grandchildren	110
4.3.2.6	Challenges with regard to caring for grandchildren.....	110
4.3.2.7	Support system	110
4.3.2.8	Resilience factors	111
4.3.2.9	Talking about sex and HIV/AIDS.....	111
4.3.2.10	Experience of losing a parent.....	111
4.3.2.11	Positive aspects to being raised by a grandparent	111
4.3.2.12	Challenges with regard to being cared for by an elderly caregiver	112
4.3.2.13	Future goals.....	112
4.3.2.14	Synthesis and conclusion of interview: case study two	112
4.3.3	Case study three: Mama Joyce's family	112
4.3.3.1	Biographical profile of Mama Joyce's family.....	113
4.3.3.2	Precipitating factors leading to grandparent fulfilling parent role to grandchildren	113
4.3.3.3	Living conditions.....	113
4.3.3.4	Financial situation.....	113
4.3.3.5	Health status of grandparent	114
4.3.3.6	Positive aspects to caring for grandchildren	114
4.3.3.7	Challenges with regard to caring for grandchildren.....	114
4.3.3.8	Support system	114
4.3.3.9	Resilience factors.....	114
4.3.3.10	Talking about sex and HIV/AIDS	114
4.3.3.11	Experience of losing a parent.....	115
4.3.3.12	Positive aspects to being raised by a grandparent	115
4.3.3.13	Challenges with regard to being raised by an elderly caregiver.....	115
4.3.3.14	Future goals	115
4.3.3.15	Suggestions for supporting agencies.....	115
4.3.3.16	Synthesis and conclusion of interview: case study three.....	115
4.4	SYNTHESIS AND INTERPRETATION OF THEMES	116
4.5	CONCLUSION.....	125

CHAPTER 5: OVERVIEW OF THE STUDY AND RECOMMENDATIONS

5.1	INTRODUCTION	126
5.2	OVERVIEW OF THE INVESTIGATION	126

5.3	OVERALL SUMMARY AND SYNTHESIS OF FINDINGS	127
5.3.1	Prevalence of HIV/AIDS	127
5.3.2	The <i>grandmothers' disease</i>	127
5.3.3	Grief of grandmothers and orphans	127
5.3.4	Sources of income	128
5.3.5	Orphans cared for by women	128
5.3.6	Challenges after AIDS deaths	128
5.3.7	Access to medication	129
5.3.8	Anxiety and its influence on learning	129
5.3.9	Grandparent-headed households and educational disadvantage	129
5.3.10	Support groups for grieving children	130
5.3.11	Orphaned adolescents and recreation.....	130
5.3.12	Emotions experienced by orphaned adolescents	130
5.3.13	Understanding of death	131
5.3.14	Dependence on government support	131
5.3.15	Grandparents as guardians to orphans of more than one adult child.....	131
5.3.16	Grandparents borrowing money	131
5.3.17	Gender of orphans in grandparent-headed households.....	132
5.3.18	Fathers of orphans	132
5.3.19	Education levels of grandparents.....	132
5.3.20	Orphans and birth registration	133
5.3.21	Grandparents and self-rated health status	133
5.3.22	Support agencies	133
5.4	RECOMMENDATIONS.....	134
5.4.1	Recommendations for schools.....	134
5.4.2	Recommendations for non-government organisations.....	134
5.4.3	Recommendations for government.....	136
5.4.4	Recommendations for helping professions	136
5.5	SUGGESTIONS FOR FUTURE RESEARCH.....	137
5.6	LIMITATIONS OF THE STUDY	138
5.7	CONCLUSION.....	138
	REFERENCES.....	139
	APPENDICES	148

APPENDIX 1: Informed consent form	148
APPENDIX 2: Informed consent form (grandparents on behalf of grandchildren)	149
APPENDIX 3: Discussion guide for grandmother focus group	150
APPENDIX 4: Discussion guide for stakeholder focus group	153
APPENDIX 5: Discussion guide for orphans focus group.....	156
APPENDIX 6: Illustration of analysis of data.....	158
APPENDIX 7: Example of exploitation of grandparents.....	162

CHAPTER 1: INTRODUCTORY OVERVIEW

1.1 GENERAL AWARENESS

My interest in the subject of HIV/AIDS stems back to the early 1990's when I was the principal of the SOS Children's Village in Port Elizabeth. I was asked in 1991 to chair a committee, on behalf of SOS Kinderdorf International, to establish policy for the organisation regarding the care of children in SOS Villages who were HIV positive and also for those who were ill from AIDS related illnesses. There were no known cases of HIV positive children in the Port Elizabeth village at that time. Drawing up policy was an interesting exercise but only of academic value because the phenomenon of HIV/AIDS seemed remote as it did not affect me directly. I was also a part-time trainer in the field of Child and Youth Care at the time and one of the courses I trained was on the subject of HIV/AIDS. I learned and taught about the myths surrounding the contracting of the HI virus, about universal precautions and read the statistics forecasting the number of deaths due to AIDS by the year 2000 and the vast numbers of orphans that there would be in Sub-Saharan Africa by the turn of the century. My perception was that these predictions were unrealistic and exaggerated and in truth they made very little impact on me. During the past year, however, the reality of HIV/AIDS impacted my life directly in that a staff member in my wife's playschool passed away due to the illness and one other staff member also became very ill and informed her employer that she had been diagnosed with the virus. One of the children in the playschool is from a local haven for HIV positive toddlers and has been taken into foster care by the manager of the haven, who is an elderly person.

1.2 ACTUALITY OF THE PROBLEM

Based on the report of the Department of Health "National HIV and Syphilis Sero-prevalence Survey in South Africa 2007" (Avert[g] 2009:1), it is estimated that 28% of pregnant women across South Africa were living with HIV in 2007. The provinces of KwaZulu-Natal, Mpumalanga and Free State recorded the highest HIV rates while the Northern Cape and Western Cape recorded the lowest prevalence.

The report of the "South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey, 2008" as quoted in Avert[g] (2009:2) indicates that an estimated 10.9% of all South Africans over two years old were living with HIV in 2008. In this survey, a

sample of people were selected to represent the general population of South Africa and of those who were eligible, 64% were willing to give a blood sample to be tested for HIV anonymously. It was interesting to note that the estimated HIV prevalence among people between the ages of 15 and 49 was 16.9% in 2008.

In 2008 Statistics South Africa as quoted in Avert[g] (2009:4) released the report, "Mortality and causes of death in South Africa, 2006". Their findings were evidently taken from death notification forms. The report shows that the annual number of registered deaths in South Africa rose by 91% between 1997 and 2006. The 25-49 years age-group reportedly showed a rise of 170% in the same nine-year period. Avert[g] (2009:5) concede that part of the overall increase could be ascribed to population growth but argue that this could not explain the 'lopsided' increase in deaths among people aged 25-49 years. In 1997, 29% of all deaths were in the 25-49 years grouping but in 2006 this age group accounted for 42%. HIV was recorded as a cause of death in only 14 783 cases in 2006 but the Medical Research Council of South Africa researchers believe that this figure is a huge underestimate because most deaths due to HIV are wrongly classified. Doctors generally record only the immediate cause of death such as respiratory infection or tuberculosis but the MRC researchers claim that if someone contracts tuberculosis and dies from it because their immune system has been compromised by HIV then HIV should be listed as one of the underlying causes. The Medical Research Council team analysed a 12% sample of death certificate data from the 2000-2001 period and compared it to all the 1996 data. They noticed that rates (deaths per thousand) had increased according to a particular age-specific pattern when they focussed on deaths for which HIV was a reported case. The biggest increases were in the 0-4 and 25-49 years age groups but death rates among teenagers and older people stayed more or less the same (Avert[g] 2009:5).

The Medical Research Council team also noticed that nine other causes of death had increased dramatically in parallel to the age pattern of HIV. They then estimated to what extent the increases could be attributed to HIV and came to the conclusion that 61% of deaths linked to HIV had been incorrectly attributed to other causes in 2000-2001. The Medical Research Council reported that in South Africa HIV caused the deaths of 53 185 men in the 15-59 years age-group, 59 445 women aged 15-59 years and 40 727 children younger than 5 years of age in the year 2000-2001 (Avert[g] 2009:5). From the aforementioned data it is clear that adults in South Africa of parenting age account for the

majority of deaths linked to HIV/AIDS. Andrews, Skinner and Zuma (2006:269) refer to a 2005 UNICEF report which states that in sub-Saharan Africa the HIV/AIDS epidemic has been a contributing factor with regard to rising child mortality and has already orphaned a generation of children. The report projects that by 2010, 18 million African children younger than 18 years of age are likely to be orphans from the single cause of HIV/AIDS. The UNICEF report states that data from across Africa shows that where the epidemic is more severe and/or the extended family is weakened, orphaned children are more likely to be cared for by grandparents.

My attention was drawn to the plight of grandmothers caring for their orphaned grandchildren when I attended an information-sharing gathering at a local church where I learned about a programme called the “Gogo Trust” which operates in a Port Elizabeth township. This programme provides support to grandmothers who function as parents to their deceased children’s children. I wondered about the guidance that the workers in this programme were receiving and realised that the aspect of guidance to psychologists and lay workers supporting grandparents caring for their grandchildren could be of real value to these dedicated people.

1.3 PRELIMINARY LITERATURE INVESTIGATION

1.3.1 International perspective

According to Gutheil and Chichin (1991:237) AIDS in the United States is a “multigenerational catastrophe” and is becoming a fact of life for older people. An increasing number of older parents and grandparents are taking on the role of caregivers of children with AIDS. Grandparents are responsible for raising grandchildren or caring for grandchildren who are HIV infected while their adult children are ill and after their deaths. The authors suggest that AIDS affects older people in direct and indirect ways: directly, when they or a loved one is HIV positive or contracts the disease and indirectly when they live near people with AIDS or when the demand for long-term care services for older people and people with AIDS is more than what the system can handle.

Joslin and Harrison (2002:619) report that around the globe, older relatives, mainly grandparents, have become the surrogate parents to children and adolescents orphaned by the death of parents from HIV/AIDS as well as to those whose infected parents are not well

enough to be their primary caregivers. The authors suggest that these older surrogate parents have, in the main, been overlooked by research and are subject to complex stress factors and face the risk of neglected and compromised health. In an initial study of third- and fourth-generation relatives, 55% rated their own health as “fair” or “poor” and 70% reported not having enough time to pay attention to their own health. The authors conclude that supportive services are necessary to respond to the health needs of these “hidden patients”.

Linsk and Mason (2004:127) investigated the needs of relative caregivers of children in the American child welfare system whose parents had HIV. The authors found that the HIV-affected extended family caregivers experienced issues related to the children’s behavioural problems, HIV-related concerns, adolescent issues, emotional difficulties and sexual abuse. They also had more concern about their health and their numerous roles. These authors also conclude that these HIV-affected caregivers need attention and intervention by social workers, child welfare workers and case managers.

1.3.2 African perspective

Webb (1997:2) suggests that Africa has been most affected by the HIV/AIDS pandemic reporting that approximately 70% of the 34 million HIV positive people around the world live in Sub-Saharan Africa and that approximately 95% of the world’s AIDS orphans are African.

Much quantitative research appears to have been done on the increasing caregiving role of the elderly due to the deaths of the middle generation. For example, Floyd, Crampin, Glynn, Madise, Mwenebabu, Mnkondla, Ngwira, Zaba and Fine (2007:787) report that around 50% of children in Northern Malawi living apart from both parents had a grandparent as their guardian. Oluwagbemiga (2007:668) reported that in his analysis of people living with HIV/AIDS in Lagos state, grandparents are assuming responsibility for raising the children as HIV/AIDS strikes at parents.

Ardington, Case, Islam, Lam, Leibrandt, Menendez and Olgati (2009:1) refer to studies from a number of African countries that show that grandparents play a major role in caring for AIDS orphans.

Some researchers have described the problems and coping strategies of children orphaned by AIDS. Mangoma, Chimbari and Dhlomo (2008:126) report that the survival wish list of orphans in Kariba, Zimbabwe included school fees, accommodation, provision of health care, adequate food and projects that generated income. Lalthapersad-Pillay (2008:148) reports that orphans in sub-Saharan Africa have to contend with conditions that are financially, socially and emotionally stressful and experience problems like hunger, having no access to healthcare, homelessness, forced migration, sexual exploitation and being the targets for child labour.

My preliminary investigation revealed that the majority of research has focussed on describing the stress experienced by caregiving grandparents and the needs of guardians taking in orphans. For example, Bock and Johnson (2008:131) report that grandparents in Botswana assume much of the childrearing responsibilities which create a lot of extra work for grandmothers in particular. They sometimes have the added stress of caring for their ill adult children. The authors conclude that when older women assume the role previously played by lost younger women, it may be detrimental to their health which in turn has a negative effect on grandchildren. Linsk and Mason (2004:127) refer to research done by Burton et al. who describe grandmothers experiencing adverse psychological functioning that result from caregiving, such as distress, depression, anger, resentment and parenting stress. These grandparents also reported lower levels of physical functioning or physical limitations that could influence their quality of life and capacity to provide care to their grandchildren.

1.3.3 South African perspective

Freeman and Nkomo (2006:302-310) report on a South African survey that was carried out across three provinces to determine current and prospective caregivers of orphaned and vulnerable children resulting from AIDS deaths. They refer to increasing warnings of the limitations of the extended family as an alternative placement option for these children.

Current caregivers who were surveyed believed that:

- their partner (30%)
- a grandparent (25%)
- another family member (33%)

would look after the child/children if they no longer were able to. The remainder (12%) could not identify a carer and predicted only a bleak future for their children.

There was a strong willingness amongst adults connected to the orphaned children to take them in if necessary: 71% of fathers, 71% of grandparents, 63% of siblings and 23% of best friends indicated that they would take in children. The authors warned, however, that willingness may not necessarily translate into reality. Most prospective caregivers mentioned significant additional stressors (mainly financial) and expressed a strong need for assistance if they were to take in extra children. It was also noted that the HIV status of the child would, for the majority of respondents, not influence their decision on whether to take in a child or not, but for a number of people this would be a deciding factor.

The authors concluded that people would need a lot of help to realise the potential of keeping children in families and for some children, alternatives other than the extended family will be required.

A media release by Dr. Monde Makiwane on behalf of the Human Sciences Research Council on 1 December 2004 (Makiwane 2004:1) described the elderly as the unsung heroes of the pandemic reporting that 60% of orphans in South Africa were being cared for by their grandparents. The media release painted a depressing picture of the living conditions of the elderly in Mpumalanga province where they spend most of their income on household needs and education of grandchildren; 9% are caring for sick young adults living in the household; 22% are staying with grandchildren whose own parents have either died or are away in the cities on a long-term basis; 20% take care of children six years or younger, and 46% take care of children between the ages of six and eighteen years. The report highlighted the fact that the physical demands placed on ageing parents are huge, especially in rural areas where access to water, electricity, food and proper infrastructure is limited or does not exist.

The report points out that even without HIV/AIDS, the younger generations is a growing problem for the elderly. Young people generally have little hope of finding jobs after completing their schooling and unplanned pregnancies among youth also compound the burden placed on grandparents who are left to look after the babies, with no significant support from the parents.

Most of the elderly were found to be victims of past policies which discriminated against them resulting in low education levels and low socio economic status. The majority of the elderly in Mpumalanga are females, as males generally die earlier. The census of 2001 revealed that there are 34 males to 100 females among the elderly in Mpumalanga.

It was also reported that older women are accused of witchcraft in some places which naturally results in stigmatisation and ostracising. The elderly are accustomed to receiving inferior service at hospitals and pension pay points. It was also stated that the elderly offer their services to a generation of youth who are perceived to be ungrateful and disrespectful to the older generation who struggle to discipline their children and grandchildren.

The HSRC report concluded that the AIDS crisis in South Africa had necessitated a need to improve understanding and co-operation between the different generations and that there was a need to acknowledge the heavy burden placed on older people by our society by giving them more subsidies on basic foodstuff and services and provide necessary information so as to cope with their new role as surrogate parents to their grandchildren.

My preliminary literature investigation led me to believe that there appeared to be a dearth of material on support for people offering support to the grandparents looking after their grandchildren. My intention was to investigate the needs of grandparents and translate these into guidelines for professionals and lay people who attempt to empower grandparents assuming the role as parents in the context of the HIV/AIDS pandemic.

1.4 PROBLEM STATEMENT

I have had preliminary discussions with facilitators from both the *Gogo Trust* as well as an organisation called the *goGogetters* (a project under the auspices of *loveLife* which deploys grandmothers as informal educators and youth mentors in communities across South Africa) and in both instances I have been extremely impressed with their resolve to ease the burdens of grandmothers caring for their HIV/AIDS affected grandchildren. It became apparent during these discussions that both organisations were breaking new ground in offering this valuable service to various communities and were learning valuable lessons that needed to be documented so that when these programmes are replicated elsewhere that the “wheel would not need to be re-invented”. It also became apparent that these programmes were in need of guidelines that would enable them to work more effectively and efficiently in

meeting the needs of these heroic, self-sacrificial grandparents and ultimately in meeting the needs of the orphaned and HIV/AIDS affected children and youth. In the context of the aforementioned discussion, the research problem of this investigation is stated as follows:

What guidelines are necessary for empowering grandparents who fulfil the role of parents in the context of the HIV/AIDS pandemic?

1.4.1 Sub-problems

In order to address the main research problem, the following sub-problems were identified:

1. What is the prevalence of HIV/AIDS?
2. What is the prevalence of grandparents assuming the role of parents to their grandchildren?
3. What are the needs of orphaned children?
4. What are the characteristics of grandparent-headed households?
5. What helping services are presently in place for grandparent-headed households?
6. How can Erikson's model of psychosocial development be applied to this problem?
7. What are the views and experiences of two grandparent-headed households?
8. What are the views of two groups of stakeholders with regard to the phenomenon of grandparent-headed households?
9. What are the guidelines for professionals and lay people who endeavour to empower grandparents fulfilling the role as parents in the context of the HIV/AIDS pandemic?

1.5 RESEARCH AIMS

In view of the main research problem and the subsequent sub-problems, the aims of the study are as follows:

1. To investigate the prevalence of HIV/AIDS.
2. To investigate the prevalence of grandparents assuming the role of parents to their grandchildren.
3. To determine the needs of orphaned children.
4. To identify the characteristics of grandparent-headed households.
5. To identify helping services presently in place for grandparent-headed households.

6. To establish how Erikson's model of psychosocial development can be applied to this problem.
7. To explore and describe the experiences of two grandparent-headed households.
8. To explore and describe the experiences of two groups of stakeholders with regard to the phenomenon of grandparent-headed households.
9. To establish guidelines for professionals and lay people who endeavour to empower grandparents fulfilling the role as parents in the context of the HIV/AIDS pandemic.

1.6 LITERATURE REVIEW

To investigate the phenomenon of orphans in general, I consulted books, journal articles, the press, reports, internet sources and conducted interviews with stakeholders. In the first section of the review which forms part of chapter two, an attempt was made to present orphanhood as a direct consequence of the HIV/AIDS pandemic. This was followed by an exploration of the factors leading to the phenomenon of grandparents assuming the role of caregivers to their grandchildren and a description of the prevalence of this phenomenon.

The second part of the literature review, which is also contained in chapter two, focussed on Erikson's ego psychological theory with a view to describing the developmental needs of orphaned children and adolescents and in particular their anticipated responses to grief during each of the developmental stages.

1.7 RESEARCH DESIGN

Yegidis and Weinbach (1996:89) describe a research design as a plan for carrying out research which sets out to find answers to the research question or for testing hypotheses that were formulated. Thomas (2009:70) similarly defines a research design as the plan for the research. He uses the analogy of designing a kitchen to explain the concept of research design. When designing a kitchen, one needs to consider a whole range of factors like what the kitchen will be used for mostly; whether one has gas on one's property; the location of the drains, water, electricity and natural light et cetera. One needs to take into account how much money one wants to spend and the type of 'feel' one is comfortable with. One may consult catalogues and kitchen design specialists and once one has done all one's fact-finding, one is now ready to draft out a sketch of one's plan. The first few drafts may need to be scrapped but finally one builds the kitchen but even at this stage one encounters a few

technical hitches. Eventually the kitchen is complete and one is pleased with the outcome but not without a great deal of planning and re-planning. Thomas (2009:92) explains that in designing one's research one firstly has to think about the purpose of the research, the kind of question (or questions) one wants to ask and one will be refining this question in the light of one's literature study. Then one needs to decide what kind of research one will do – which paradigm one will be working within and how this influences one's kind of analysis. Then one has to decide which kind of design frame one will use (case study, experiment, et cetera) followed by the techniques one will use to gather data.

1.7.1 Demarcation

In order to investigate the research problem stated in 1.4 above, a qualitative research approach was followed. Strauss and Corbin (1998:10-11) define qualitative research as any type of research which produces findings that are not arrived at by statistical methods or other forms of quantifying data. It may also refer to research concerning people's lives, their emotions and feelings but also to the functioning of organisations, social movements, cultural aspects and contacts between nations. I made use of *focus groups* and *case studies*, both being forms of qualitative research. Bell (2005:162) explains that a *focus group* is one form of group interviewing and as its name indicates its purpose is to focus discussion on a certain issue. She explains that focus groups tend to include members who either have similar experience (for example, they may all have had the same type of illness) or share a common professional concern about the issues to be discussed. Laws (2003) is quoted in Bell (2005:162) suggesting that focus groups are useful when in-depth information is needed about how people think about an issue – their reasoning about why things are as they are and why they hold the views they do. Lichtman (2010:81) describes a *case study* as an approach to qualitative research which involves an in-depth examination of a specific case or several cases. A case may be limited to a characteristic, trait, behaviour, or particular situation. I selected two grandparent-headed families as well as a Non Government Organisation (focusing on the needs of grandmothers) as case studies.

1.7.2 Selection of respondents

For the purpose of the empirical investigation the following respondents were selected:

Focus groups:

- A group of orphans in Port Elizabeth between the ages of fourteen and nineteen years being cared for by elderly grandparents;
- stakeholders in the form of co-ordinators from two established Non Government Organisations in Port Elizabeth as well as a church pastor and community leader offering support to grandmothers fulfilling the role of parents to their orphaned grandchildren and;
- a group of grandmothers in Port Elizabeth sixty years of age and older caring for orphaned grandchildren.

Case studies:

- Two families in Khayelitsha and Meadowlands respectively consisting of orphans between the ages of fourteen and nineteen years where a grandparent sixty years of age or older had assumed the role of parent(s) to their children's children;
- A Non-government Organisation called Grandparents Against Poverty and AIDS (G.A.P.A.) operating in the township of Khayelitsha in Cape Town.

I selected respondents using *purposive sampling* which is one broad type of *non-probability sampling* (the other, according to Ary, Jacobs, Razavieh and Sorensen [2006:174], being *convenience and quota sampling*). According to Arber (1993:71) *purposive sampling* is where the chance of selection for each element in a population is unknown and is even zero for some elements. Where the researcher's goal is to develop theory and a broader understanding of social processes or actions, the representativeness of the sample may be less important and the best sampling method may be purposive sampling. The specific purposive sampling method I used to select respondents for the focus groups was *snowball sampling*. Arber (1993:74) explains that this approach involves contacting a member of the population of interest and asking whether they know anyone else with the required characteristics. These people are interviewed in turn and they too are asked the question. *Snowball sampling* can only be used when the target sample members are involved in a form of network with others who have the same characteristic of interest, for example, grandmothers belonging to a *gogo* support group.

1.7.3 Data collection

1.7.3.1 Data collection for focus groups

As mentioned I also made use of *focus groups* as part of my empirical investigation. Toseland & Rivas (2005:358) explain that focus group meetings consist of a semi-structured interview and discussion with six to twelve group members facilitated by a moderator. In each group I recorded the meeting using an audiotape and ensured that there was no distracting noise outside the venue during the meeting. I also invited a Xhosa speaking person to help with translation where necessary and to check on the recording equipment. I used a discussion guide (see appendices 3,4 and 5) that I had drawn up from relevant questions that I needed answers to. I tried to direct the group to discuss the matters included in the discussion guide through giving a few “prompts” but without dominating the proceedings. When new topics emerged I allowed the discussion to continue unless I felt that it was heading away from issues that I needed to be addressed.

1.7.3.2 Data collection for case studies

The primary technique used to gather data was the interview, specifically the *semi-structured interview*. Kvale (1996:2) refers to a qualitative research interview as a “construction site of knowledge”. He regards an interview as literally being an *inter view*, an inter change of views between two people talking about something of mutual interest. In an interview conversation the researcher listens to what people say about their own lived world, hears their opinions and learns about their perceptions of their work situation, family life as well as their hopes and dreams. I used this technique because I believed that it would produce relevant data which could be translated into guidelines for schools, non-government organisations, government and helping professionals offering support to grandparents.

Fielding (1993:136) differentiates between the following types of interviews:

Standardised or structured interviews, where an interview schedule is used and the wording of questions and the order in which they are posed is the same from one interview to the next;

Semi-standardised or semi-structured interviews, where the researcher asks certain, major questions the same way each time but is free to change their sequence and to probe for more data and;

Non-standardised or unstructured interviews, where researchers have a list of topics they want the interviewee to talk about, but have the liberty to phrase the questions as they like, ask them in any order they deem fit and even join in the conversation by sharing their own views on the topic themselves.

I made use mainly of the semi-structured interview as it allowed me to adapt to the level of comprehension of the respondents and accommodated the fact that in responding to a question, people sometimes also give answers to questions that were going to be asked later.

I obtained permission from both families identified for my case studies as well as the management team of G.A.P.A. to tape record the respective interviews and to transcribe them and assured them of confidentiality in the research report for ethical reasons. The G.A.P.A. management team, however, were willing for their names to be published. I used a small unobtrusive tape recorder and kept note-taking to a minimum to facilitate the free flow of data and communication. My introduction to both families as well as to the G.A.P.A. personnel, which included a brief explanation of the purpose of the study and minimal information about me, was similar.

I recorded the issues that I had anticipated the respondents focusing on during the interview (having encountered them during my literature investigation), on a grid before each session. I then marked the issues as they were covered during the interview. Issues that emerged which, in my view, needed further clarification and new trends and dynamics that I observed during the interview were also marked down. I then ensured that the issues were clarified either immediately or before the end of the session.

1.7.4 Data analysis

1.7.4.1 Data analysis for focus groups

After each focus group I transcribed the audiotape to analyse the content. I basically followed the method of analysis suggested by Ary et al. (2006:490) which consists of:

- Familiarizing oneself with the raw data (by reading the transcriptions a number of times) and organizing it into a rudimentary coding system using units of meanings like words, phrases, sentences, behaviour patterns and events that seemed to appear repeatedly and seemed important;
- Coding and recoding the data by placing all units of meanings with the same or similar codes together ensuring that they belonged together. I then tried to group related codes into larger categories and in turn looked for categories that could be linked to form major categories or themes. I followed this process for each transcript.
- Summarizing the data by finding links and connections between categories and finally interpreting the data by attempting to analyse what was meant, inferred or implied by participants' responses and providing some context to their responses.

1.7.4.2 Data analysis for case studies

After transcribing the interview tapes, I conducted a data analysis employing the method proposed by Ary et al. (2006:490) which is very similar to that suggested by Lichtman (2010:198) namely:

Step 1: Initial coding – extracting some central idea from the responses.

Step 2: Revisiting the initial coding.

Step 3: Developing an initial list of central ideas or categories.

Step 4: Modifying one's initial list based on additional re-reading.

Step 5: Revisiting one's categories and subcategories.

Step 6: Progressing from categories to concepts or themes.

Steps 1-5 consist of a data analysis whereby the initial/original data is transcribed and read more than once to extract a general idea from the responses. Thereafter a list of important/relevant categories is developed. The list is modified by re-reading the transcriptions. In step 6 there is a progression from categories to concepts or themes. As a means of context analysis, meaning is added by taking the context of the interviewees into account (or by adding the context to the data).

1.8 VALIDITY AND RELIABILITY

According to Ary et al. (2006:504) *validity* in qualitative research has to do with the accuracy or truthfulness of the findings. The term *credibility* is often used by qualitative researchers as a synonym to *validity* and answers the following questions: How confident can you be in the researcher's findings? Are they believable? Bell (2005:117) refers to a definition of *validity* given by Sapsford and Jupp (1996) where they explain that it is the design of research to give credible conclusions and where the evidence which the researcher puts forward is worthy of the interpretation that is put on it. McMillan and Schumacher (2001:407) define the *validity of qualitative designs* as the degree to which the interpretations and concepts have the same meanings for the participants as they do for the researcher. I attempted to enhance the validity of my findings through *triangulation* which according to Thomas (2009:111) is a term which was borrowed from surveying and geometry referring to the use of fixed reference points organised in triangles where by knowing an angle and the length of two sides of a triangle, the third can be worked out accurately and distances can be checked and cross-checked. In social science *triangulation* refers to the fact that viewing a phenomenon from several points is preferable to viewing it from only one. I looked at the phenomenon of grandparent-headed households from the perspectives of stakeholders, grandparents and the orphans in these households to corroborate data. I believe the validity of my findings was also enhanced by the fact that I recorded the various interviews and focus group interviews using a tape recorder which enabled me to obtain literal statements and quotations of participants.

Ary et al. (2006:509) suggest that qualitative researchers use the terms *dependability* or *trustworthiness* rather than *reliability*. In quantitative research *reliability* has to do with consistency of behaviour or the measure to which findings would be similar if the study were to be repeated. In qualitative studies, however, we expect that findings would vary because the context would be different in a replicated study. Therefore, consistency is seen as the extent to which variation can be tracked or explained. Reliability is enhanced when the researcher can demonstrate that his or her methods are reproducible and consistent, that the approach and procedures that the researcher used were apt and can be documented, and that external evidence can verify conclusions that were drawn. In my view my research is dependable in that my findings were consistent across a number of settings and were corroborated through similar findings from various data sources.

Thomas (2009:106) controversially suggests that reliability is irrelevant in interpretative research.

1.9 ETHICAL CONSIDERATIONS

I made every effort to carry out the empirical investigation consistent with ethical guidelines. Unfortunately Unisa does not yet have a system of ethical clearance in place. A committee was recently established and the process according to which students must apply is evidently still being developed according to Venter (2011: personal interview). Permission was sought from all relevant stakeholders, including children and grandparents, who were involved in the investigation. Thomas (2009:149) cautions that more than simple agreement is needed – informed consent is needed – potential participants should have a good idea of what they are agreeing to. Participants were given sufficient information about the study to allow them to decide to participate or not and were not coerced in any way. Informed consent forms (see Appendix 1) were given to participants to sign once they had been provided with all the information relevant to the research and expressed their willingness to voluntarily participate. The grandparents of the orphans were also requested to sign consent forms on their behalf (see appendix 2). I also ensured that the identities and interests of those involved were protected and that the confidentiality of the information given to me was respected. It is my intention that the outcome of the research project will be to the benefit of all.

1.10 STUDY PROGRAMME

The first chapter of this research report provided an introduction and general orientation to the research report and focused on the following: General awareness; actuality of the problem; preliminary literature investigation; problem statement and sub-problems; research aims; literature review; research design which included the demarcation, selection of respondents and media used; validity and reliability; ethical considerations and an outline of the study programme.

Chapter two focused on the HIV/AIDS pandemic providing data from an international, continental and national perspective. An overview of organisations providing support to grandparent-headed households was also given. The nature and prevalence of grandparent-headed families as a result of the HIV/AIDS pandemic was also discussed in chapter two.

The chapter also explained Erikson's theory of psychosocial development as a conceptual framework for this research.

Chapter three focused on my application of the qualitative research process.

Chapter four presented an analysis and interpretation of the research data.

The final chapter outlined the overall conclusions and presented guidelines to professionals and lay people offering support to grandparents in their role as parents to their orphaned grandchildren in the context of the HIV/AIDS pandemic.

1.11 CONCLUSION

In this chapter, an exposition of the main research problem, sub-problems and the aims of the investigation have been presented. In the next chapter the HIV/AIDS pandemic worldwide, including Africa and South Africa, was examined.

CHAPTER 2: LITERATURE STUDY

2.1 INTRODUCTION

The previous chapter introduced and provided a general orientation to the research report. This chapter examines the phenomenon of grandparent-headed households firstly by reviewing current knowledge of the HIV/AIDS pandemic - which has been the catalyst, especially in Africa, to the increase in grandparent-headed households – from an international, continental, national and regional perspective. Secondly, chapter two investigates the prevalence of grandparent-headed households in Africa as well as internationally. Thirdly, the holistic needs of orphaned children and adolescents are explained. The psychosocial needs in particular of orphaned children are examined according to Erikson's theory of psychosocial development. This chapter also describes the characteristics of grandparent-headed households, both in Africa and internationally. Lastly the chapter provides an overview of organisations providing support to grandparent-headed households.

2.2 PREVALENCE OF HIV/AIDS

2.2.1 Global HIV/AIDS estimates

The UNAIDS Report on the Global AIDS Epidemic (2009:6) indicates that the number of people living with HIV/AIDS has risen from approximately 8 million in 1990 to an estimated 33,4 million people worldwide living with HIV/AIDS in 2008. Adults by far made up the majority of this figure (31,3 million) while there were estimated to be 2,1 million children living with HIV/AIDS. In the same year approximately 2,7 million people were newly infected with the HI Virus. There were estimated to be 2 million AIDS deaths including approximately 0,28 million child AIDS deaths in 2008. Women accounted for 50% of all adults living with the virus worldwide. In developing and transitional countries, 9,5 million people are in immediate need of antiretroviral treatment but only 4 million have access to it. It was reported that more than 25 million people around the world have died of AIDS since 1981.

According to Avert[a] (2009:1) it is estimated that worldwide more than 15 million children younger than 18 years have been orphaned as a result of AIDS. The UNAIDS Report (2010:24) shows that in 2009 there were 16 million orphans worldwide due to AIDS.

Santrock (2006:448) suggests that AIDS related deaths have begun to decline in the United States because of education and the development of more effective drug treatments. Avert[c] (2009:1) paint a bleaker picture with regard to the situation in the United States by pointing out that HIV prevention efforts have not always been successful and each year almost 56 000 Americans are infected with HIV. In March 2009, according to this report, Washington DC had an HIV prevalence rate of at least 3% among people over 12 years. HIV positive people are still stigmatised and discriminated against and thousands of uninsured Americans have difficulty accessing effective HIV care and antiretroviral treatment. The world's largest donor of funding for AIDS-related projects is itself facing a major AIDS epidemic. The UNAIDS Report on the Global AIDS Epidemic (2010:50) reports that the total number of people living with HIV in North America and Western and Central Europe continues to grow and reached approximately 2.3 million in 2009 – 30% more than in 2001. It is interesting to note that African Americans are disproportionately affected by the AIDS epidemic – to date 40% of AIDS related deaths in the United States have been among black Americans. UNAIDS (2010:50) reports a similar finding stating that in the United States of America, African-Americans make up 12% of the population but accounted for 45% of the people newly infected with HIV in 2006. According to the same report, in 2009, women comprised about 26% of the people living with HIV in North America.

Asia remained relatively unaffected by the pandemic in the early to mid-1980's but by the early 1990's, the pandemic had 'reached' several Asian countries and by the turn of the century HIV was spreading very quickly in many areas of the continent. Today, almost 4,7 million people are living with HIV in Asia. Each country in the region faces a unique situation, however. In countries like Cambodia, Myanmar and Thailand there has been evidence of a decline in HIV prevalence but on the other hand, in Indonesia, Pakistan and Vietnam the number of people living with HIV has increased. There have even been warnings that epidemics in Asia could reach levels similar to those in some parts of Africa (Avert[d] 2009:1). UNAIDS (2010:34) states that in 2009, an estimated 4.9 million people were living with HIV in Asia, about the same as five years earlier which shows that most national HIV epidemics appeared to have stabilized. This report concurs with Avert (2009[d]) that in countries like Bangladesh, Pakistan (where drug injecting is the main mode of HIV transmission) and the Philippines, HIV prevalence is increasing.

In 2008 approximately 1,5 million people in Russia, Eastern Europe and Central Asia were living with HIV. Of those, 110 000 became infected that year while 87 000 people died of AIDS. It is believed that more than two-thirds of the area's infected people live in Russia, and together with

Ukraine, account for 90% of the region's total infections. Since 2001, HIV prevalence in Russia, Eastern Europe and Central Asia has more or less doubled, making this region the world's most rapidly expanding epidemic (Avert[e] 2009:1). UNAIDS (2010:38) reports similar findings stating that the number of people living with HIV in this region has almost tripled since 2000 and reached an estimated total of 1.4 million in 2009 compared with 760 000 in 2001.

It is estimated that approximately 850 000 people were living with HIV in Western and Central Europe at the end of 2008. UNAIDS (2010:21) reports that in 2009, 820 000 adults were living with HIV in Western and Central Europe and 8500 adults and children died as a result of AIDS. Despite the number being relatively small compared to sub-Saharan Africa for example, it is still regarded as a major public health issue. More recent evidence, according to Avert[f] (2009:1), shows increasing rates of HIV transmission in many European countries especially among men who have sex with men. The number of people dying from AIDS in this region, however, has decreased significantly since the advent of combination antiretroviral treatment in the mid-1990's. HIV is now considered by many to be a chronic disease as opposed to a death sentence.

2.2.2 HIV/AIDS in Africa

Dawes et al. (2007:359) point out that even though sub-Saharan Africa makes up only 10% of the world's population, 64% of those living with AIDS live in the sub-continent. This translates to a figure of 22, 4 million people. Avert[b] (2009:1), quoting from the UNAIDS 2009 report, indicate that in 2008 around 1,4 million people died from AIDS in sub-Saharan Africa and 1,9 million people became infected with HIV. UNAIDS (2010: 20) reports that a year later, in 2009, there were 22,5 million adults and children living with HIV in Sub-Saharan Africa (68% of the global total) and there were 1,3 million deaths among adults and children in this region in 2009. UNICEF (2006:iv) predicts that by 2010, an estimated 15.7 million children will have lost at least one parent due to AIDS in sub-Saharan Africa. It is expected that the AIDS death toll in sub-Saharan Africa will continue to rise due to a lack of expanded prevention, treatment and care efforts and that the full impact of the AIDS pandemic on this region will only be felt in the course of the next ten years and beyond (Avert[b] 2009:1).

The HIV prevalence rates and the numbers of people dying from AIDS differ significantly between African countries, according to Avert[b] (2009:2). For example, in Somalia and Senegal the HIV prevalence is less than 1% of the adult population – UNAIDS (2010:28) similarly reports that the adult HIV prevalence in 12 countries [including Senegal] was estimated at 2% or less - , whereas

in Namibia, South Africa, Zambia and Zimbabwe approximately 15-20% of adults are infected with HIV. It was shocking to learn that in Botswana, Lesotho and Swaziland the national adult HIV prevalence rate now exceeds 20%. This fact is corroborated by UNAIDS (2010:28) which states that at an estimated 25.9% in 2009, Swaziland has the highest adult HIV prevalence in the world.

Evidently West Africa has been affected to a lesser extent by HIV and AIDS but some countries are experiencing increasing HIV prevalence rates. In Cameroon, for example, HIV prevalence is now at around 5,1% and in Gabon it stands at 5,9%. Nigeria has a relatively low prevalence rate (3,1%) compared to other African countries but, being the most populated country in sub-Saharan Africa, the number still equates to 2,6 million people living with HIV. These statistics are very similar to those put out by UNAIDS (2010:28) which reports that the prevalence of HIV is highest in Cameroon at 5,3%, Gabon at 5,2% and Nigeria at 3,6%.

In the East African countries of Uganda, Kenya and Tanzania adult HIV prevalence is more than 5%, according to Avert[b] (2009:2). UNAIDS (2010:28) reports that the epidemics in East Africa have declined since 2000 but are stabilizing in many countries. The HIV incidence in the United Republic of Tanzania slowed to about 3,4 per 1000 people between 2004 and 2008; the national HIV prevalence in Kenya dropped from about 14% in the mid-1990s to 5% in 2006; the HIV prevalence in Uganda has stabilized at between 6,5% and 7% since 2001.

2.2.3 HIV/AIDS in South Africa

Before the advent of HIV and AIDS in South Africa (the first reported case being in 1982) our country had a steadily decreasing mortality rate and a rise in life expectancy. The situation has obviously changed dramatically with the life expectancy of the South African population decreasing from 63 years in 1990 to 48 years in 2006 (UNAIDS 2006b as quoted in Smit [2007:163]). Dawes et al. (2007:359) report that there are 5,5 million South Africans living with AIDS (18,8 % of the country's adults). This figure is approximately 2% higher than that reported in the South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey, 2008 (mentioned in previous chapter) but corroborated by Aids Foundation South Africa (2009:3) which reports that in 2008 South Africa had the highest number of people infected globally, estimated at around 5,3 million, including 220 000 children under the age of 15 years. UNAIDS (2010:28) reports that with an estimated 5,6 million people living with HIV in 2009, South Africa's epidemic is the biggest world-wide. Nicolay (2008:1), who compiled the ASSA2003 AIDS and Demographic model, estimates that 5,6 million South Africans were HIV positive in 2008. She reported that different

provinces, however, experience different levels of HIV infections and AIDS related deaths which illustrated the fact that the epidemic is in different stages of development in each province and that a different approach to addressing the epidemic is necessary to curb the spread of new infections and deaths.

Statistics emanating from the 2009 National Antenatal Sentinel HIV and Syphilis Prevalence Survey in South Africa released by the National Department of Health (2010:2) were not vastly different from those mentioned in the previous paragraph. They reveal that HIV prevalence in the adult population (aged 15-49) was estimated at 17,8%; 5,63 million adults and children were infected with HIV and AIDS. Of these, 5,3 million were adults 15 years and older, 3,3 million were females and 334 000 were children. It was estimated that 314 000 South Africans - 284 000 of whom were adults - died of AIDS in 2009. There were approximately 1,95 million AIDS orphans in South Africa in 2009, according to the sentinel surveillance data using the Spectrum model. In 2009 approximately 1,58 million South Africans older than 15 years and approximately 158 000 children required Anti Retroviral Therapy.

According to Nicolay (2008:4) Kwazulu-Natal has the most severe HIV epidemic in the country with a total of 1,6 million people (16% of the population) and almost one third of all adults estimated to be HIV positive in 2008. The epidemic, in her view, has reached a mature phase meaning that AIDS deaths and new infections are more or less at the same level so that the total numbers of infected people remain constant. Data from *The 2009 National Antenatal Sentinel HIV and Syphilis Prevalence Survey* (Department of Health 2010:4) revealed that KwaZulu-Natal once again recorded the highest HIV prevalence among antenatal women with 39,5% of the population in that province being HIV positive.

Gauteng has the second most severe HIV epidemic in the country with a total of 1,4 million people (15% of the population) and one in every five adults estimated to be HIV positive in 2008. The epidemic has also reached a mature phase in this province with AIDS deaths and new infections levelling off. *The 2009 National Antenatal Sentinel HIV and Syphilis Prevalence Survey* (Department of Health 2010:31) revealed a HIV prevalence of 29,8% among antenatal women in Gauteng Province.

My province, the Eastern Cape, has the third highest number of HIV positive people in South Africa, according to this model, with a total of 730 000 (11% of the population) and one in every five adults estimated to be HIV positive in 2008. The epidemic here has not reached a mature

phase yet and is still growing rapidly with new infections doubling the number of AIDS related deaths. Dorington et al. (2002) as quoted in Katalan (2003: 42) predicted that by this year (2010), 1 201 843 people out of 7 680 901 living in the Eastern Cape would be diagnosed with HIV. They also estimated that the population cumulative AIDS deaths number in the Eastern Cape would reach a total of 619 634 in 2010. Data from the *2009 National Antenatal Sentinel HIV and Syphilis Prevalence Survey* (Department of Health 2010:31) showed that 28,1% of antenatal women in the Eastern Cape were HIV positive in that year.

There are nearly half a million HIV positive people in the North West Province. Approximately 13% of the population and one in every five adults were estimated to be HIV positive in 2008. The epidemic in this province also has not reached a mature phase yet with there being more new infections than AIDS related deaths. HIV prevalence among antenatal women in the North West Province stood at 30% according to the *2009 National Antenatal Sentinel HIV and Syphilis Prevalence Survey* (Department of Health 2010:31).

Mpumalanga has just less than 500 000 HIV positive people. Around 13% of the population and one in every five adults were estimated to be HIV positive in 2008. The epidemic here is reaching maturity with new infections and AIDS related deaths approaching 40 000 each year. Data from the *2009 National Antenatal Sentinel HIV and Syphilis Prevalence Survey* (Department of Health 2010: 31) reflected that 34,7% of antenatal women in this province were HIV positive in 2009.

The Free State has approximately 400 000 HIV positive people which represents about 14% of the population and one in every five adults were estimated to be HIV positive in 2008. Here, the epidemic is reaching maturity with new infections and AIDS related deaths coming close to 34 000 per annum. 30,2% of antenatal women in the Free State were HIV positive according to the results of the 2009 survey (Department of Health 2010:31) referred to previously.

Limpopo has almost 400 000 HIV positive people which represents more or less 7% of the population and 14% of adults between the ages of 20 and 64 were HIV positive in 2008. The epidemic is still growing with new infections almost double the number of AIDS related deaths. The 2009 survey (Department of Health 2010:31) showed that in Limpopo 21,4% of antenatal women were HIV positive.

The Western Cape has less than 300 000 HIV positive people which represents around 6% of the population – the lowest HIV prevalence rate in any single province and one in every ten adults

were estimated to be HIV positive in 2008. The epidemic is still growing with new infections much higher than the number of AIDS related deaths. The 2009 survey (Department of Health 2010:31) confirmed that the Western Cape had the lowest HIV prevalence estimate with 16,9% of antenatal women in this province being HIV positive.

The Northern Cape has 67 000 HIV positive people which is the lowest number of people living with the virus in the country. This number represents about 7% of the population and one in every 10 adults who were estimated to be HIV positive in 2008. The epidemic is still growing with new infections almost double the number of AIDS related deaths. In 2009 the estimated HIV prevalence among antenatal women in the Northern Cape was 17,2% (Department of Health 2010:31).

2.3 PREVALENCE OF GRANDPARENT-HEADED HOUSEHOLDS

The HIV and AIDS pandemic and the high adult mortality rate have made a huge impact on the structure of families and households in South Africa. Crothers (2001) is quoted in Smit (2007: 166) explaining that AIDS has brought about “household demographic structures hollowed out with only grandparents and children present.” Smit (2007:166) points out that it has been customary in African families in South Africa for grandparents to take part in the socialisation of children but now have no other option but to take on the full responsibility of raising and supporting their grandchildren whose parents have died of AIDS. They no longer can afford the luxury of being only part of what Barolsky (2003) as quoted in Smit (2007:166) called “the web of complementary socialising agents within communities.” For this reason AIDS has been referred to in South Africa as “the grandmothers’ disease” (SASIX 2010:1).

In the closing session of the 16th International AIDS Conference held in Toronto in 2006, the former UN Special Envoy for HIV/AIDS in Africa, Stephen Lewis, described African grandmothers as the “unsung heroes of the continent: these extraordinary, resilient, courageous women, fighting through their inconsolable grief [at the loss] of their adult children, becoming parents again in their fifties and sixties and seventies.... [struggling] with the nightmare of what happens to my grandchildren when I die?” (Ferreira 2007:17).

Barnett and Blaikie (1992) are quoted in Dayton and Ainsworth (2002:3) stating that the elderly are particularly vulnerable to the negative effects of the death of prime-aged adults from AIDS. They may, for example, find themselves in households where there are no economically active adults and perhaps left with the care of young and orphaned children. Bicego et al. (forthcoming) as

quoted in Dayton and Ainsworth (2002:3), in an analysis of Demographic and Health Survey data from sub-Saharan Africa, found that orphaned children are more likely than others to live in grandparent-headed households.

According to Eddy and Holborn (2011:1) in 2009, 8% of children younger than 18 years of age in South Africa lived with their grandparents.

Monasch and Boerma (2004) as quoted in Ferreira (2007:11) report that in South Africa 60% of orphans (due to AIDS) live in a grandparent-headed household. South African elders may look forward to a peaceful old age and care from family members, but many will be thrust back into the role of primary care giver to family members affected by AIDS (Ferreira 2007: 2).

The Study to Understand and Foster the Functioning and Involvement of Contributive Elders (SUFFICE), using a non-random convenience sample of 55 “potentially contributive” elders drawn from the sites of three NGOs that serve older persons in the townships of the Cape Peninsula, found that the total number of family members cared for by this group - with a mean age of 73.1 (ranging between 65-88 - was: adult children 45, grandchildren 76 and great-grandchildren 4. Twenty eight subjects reported that they are mainly responsible for raising co-resident grandchildren, while six shared the responsibility (Ferreira et al. 2007:16).

Anecdotal evidence I obtained by contacting the pastors of seven churches and the principals of eight schools in townships around Port Elizabeth suggests that between 43-45% of households are headed by grandparents in this area. Two of the schools were able to provide the actual number of their learners who lived in grandparent-headed households as they kept a record of this phenomenon.

According to Howard, Phillips, Matinhure, Goodman, McCurdy and Johnson (2006:3) 53% of caregivers of orphans in Zimbabwe are grandmothers – mostly maternal grandmothers. It appears that the African proverb, “It takes a village to raise a child” does not always apply. According to Mudavanhu (2008:9) marriage in Zimbabwe has become a contract between two individuals which leads to weaker links between and within extended families and when children from these unions are born they are no longer the collective responsibility of communities. Foster and Williamson (2000:42) suggest that in Zimbabwe as the number of orphans in a community increases and uncles and aunts (the traditional first choice as substitute caregivers) become unavailable, grandparents take on the role of caregivers – often as a last resort because other relatives refuse.

The authors report that in Zimbabwe, 78% of caregivers of orphans are grandparents, in Kenya, 65% of caregivers of orphans are grandparents compared to 36% in Uganda and 41% in Tanzania. The data shows that grandparents more often take on the care giving role to orphans where the AIDS epidemic is more severe or where the extended family is weakened.

Minkler (1999:199) explains that in the United States more than one in ten grandparents has primary responsibility for raising a grandchild at some point, with this care often lasting for a number of years.

Knodel and his colleagues (2000) as quoted in Dayton and Ainsworth (2002:3) reported that 74% of the double orphans due to AIDS in their sample of AIDS cases in Thailand were cared for by grandparents.

2.4 NEEDS OF ORPHANED CHILDREN

“When a mother dies, children suffer.” These words were spoken by a 9-year old South African boy who was orphaned by AIDS (Giese 2002:15). According to UNAIDS (2004:9) the most severe impact on children, apart from illness and death, is the death of one or both parents which often results in loss of affection, support and protection. Evidence shows that orphans living with extended families or in foster care, in addition to psychological trauma, are often subjected to discrimination and are at risk of not receiving health, education and other much-needed services.

2.4.1 Physical needs

The HIV/AIDS pandemic, according to UNICEF (2010:1), together with floods, droughts, increasing food prices, armed conflict and economic recession have broken the spirit of many families in a large part of sub-Saharan Africa. The crisis in Africa has brought the world’s attention to the severe nutritional needs of all children who are HIV positive or affected by HIV/AIDS, such as orphans and those living with infected family members. The rates of under-nutrition are increasing and orphans are the worst affected. This report claims that almost 50% of infected infants will die before their second birthday if they are not treated.

The loss of a parent due to AIDS can negatively affect an orphan’s access to basic needs like shelter, food, clothing and health. Orphans tend to live in large, female-headed households where more people are dependent on fewer income earners which places additional strain on AIDS

orphans to contribute financially to the household. In some cases this becomes a 'push factor' which results in them living on the streets working, begging or seeking food. Most children who have lost a parent carry on living in the care of a surviving parent or family member but often have to take on the responsibility of domestic chores, looking after siblings and caring for sick or dying parent(s). Children who have lost one parent to AIDS are likely to lose the other parent also because HIV may have been transmitted between the couple through sex. (Avert[a] 2009:3)

Meursing (1997) is quoted in Mudavanhu (2008:24) suggesting that even after patients have died from AIDS, surviving family members experience severe hardship in trying to cope with the economic setback as a consequence of the illness. He argues that the future for orphans is often bleak and set to become even bleaker over time. UNICEF (2003:29) reported that children orphaned by AIDS face a higher risk of malnutrition and stunting compared to non-orphans.

According to the Commission on HIV/AIDS and Governance in Africa [CHGA] (2004:17) many of the AIDS orphans are HIV positive themselves and therefore have special needs such as medical treatment and may also not be able to take part in the same activities as uninfected children because of illness, fatigue and other health challenges. Participants at an interactive conference, organised by CHGA, which took place in Cameroon in 2004, claimed that orphans often face the challenge of not having access to medication, especially anti-retroviral therapy (ART). Interestingly, it was also emphasised at this interactive conference that gender discrimination and challenges to orphans reinforced each other in several ways. Girl orphans, being both girls and orphans are doubly vulnerable, and particularly exposed to sexual abuse and other forms of exploitation and that they had even lower access to health services (CHGA 2004:8).

Family Health International (2001:4) suggests that in order for the needs of orphans and other vulnerable children to be fully met, they and their guardians need to have access to appropriate health care including clinical and preventive health care services, nutritional support, palliative care and complementary home-based care as well as full and relevant information.

2.4.2 Educational needs

"The learning process breaks down when parents die. Someone has to ensure that knowledge and skills are imparted, to enable these children to grow up to become integrated members of the community" *Gabriel Rugalema, Food and Agriculture Programme of the United Nations* (Commission on HIV/AIDS and Governance in Africa 2004:16).

Boler and Carroll (2003:1) report that there is clear evidence that orphans are dropping out of school at a higher rate than non-orphaned children. The authors point out that previous research has dealt mainly with the impact that orphanhood has had on enrolment. UNICEF (2006:13) for example, refer to an analysis based on 19 Demographic and Health Surveys in 10 sub-Saharan countries which found evidence of orphans having lower school enrolment rates than non-orphans in the same household. Boler and Carroll (2003:1) suggest, however, that it is important to also keep the quality and consistency of attendance in mind. When parents die the amount of resources available for education diminishes and, as a result, there is a greater chance of orphans dropping out of school compared to non-orphans, when school fees become too costly. According to UNICEF (2006:22) the danger of missing school seems to be greatest for double orphans and interestingly the contrast between the attendance of double orphans and non-orphans (living with at least one parent) is most prominent in countries where attendance is already low. A study in Uganda found that while almost 14 per cent of primary-school learners with both parents alive stopped going to school at some point, the proportion of double orphans missing a term was far higher, at 27 per cent. This disparity was even more pronounced in secondary school where 43 per cent of double orphans missed a term compared to 16 per cent of non-orphans. Boler and Carroll (2003:1) suggest that AIDS-related stigma in the classroom and discrimination on the part of teachers, fellow-learners and parents, which contravene the principles of Education for All, can also cause children to drop out of school. UNICEF (2006:22) quotes a South African teenager who said, "Even my friend told me she won't eat with me again. One told me right to my face that I've got AIDS and should stop going to school and stay at home. I would feel terrible. Cry deep down. I would sit alone and cry alone. People would be staring at you saying nothing, even those who used to be happy when they see you were not anymore." It needs to be borne in mind that children may be enrolled at school but may not be learning because they are hungry; they may be anxious about loved ones at home which may prevent them from concentrating or missing classes to look after their family. UNICEF (2006:12) cites an example from a Human Rights Watch study (2005) which documented the circumstances of a 40 year-old woman living in a slum in Nairobi, Kenya, caring for eight orphans in addition to her own seven children. The only possessions these orphaned children had were the clothes they were wearing because their relatives took everything when the parents died. This woman uses the money she gets from selling vegetables to send the eight orphans to an unregulated 'informal school' in the slums. She claims that the hardest thing for her is sending them to school on an empty stomach. Boler and Carroll (2003:2) call for research that looks at the spectrum of possible disadvantages faced by these children including educational

progression and outcome variables like repetition, highest grade completion, gender equity and the inclusivity of education.

As mentioned there is evidence that orphaned children are at a disadvantage educationally but Boler and Carroll (2003:2) indicate that little is known about how much of this disadvantage took place before the parent died. They claim that little data exists on the educational problems faced by children whose parents have AIDS. In this regard UNICEF (2006:22) reports that an analysis of population survey data from Kenya found that children whose parents were HIV positive are significantly less likely to attend school than children of HIV negative parents. UNICEF (2006:22) also refers to research conducted by Ainsworth, Beegle and Koda (2005) in rural Tanzania which revealed that children with ill parents are more likely to have their schooling interrupted and to spend less hours in school before their parents' death than other children. Boler and Carroll (2003:2) point to research done in Manicaland (Zimbabwe) which showed that losing a mother has a more detrimental effect on a child's primary school completion than losing a father because mothers place more priority on their children's education compared to fathers. The research also showed that the likelihood of educational disadvantage increases as time progresses since the parent's death.

The United Nations Department of Economic and Social Affairs/Population Division (UN DESA) report on the Impact of AIDS on Households (2008:50) suggests that despite the fact that grandparent-headed households tend to be female-headed and poor, living with a grandparent is generally associated with higher educational enrolment for orphans than is living with other relatives, especially more distant relatives. UNICEF (2006:22) confirms this point stating that the closer the biological tie, the greater the chance the child will go to school consistently, notwithstanding the poverty level. The closest relatives like mothers and grandparents seem to make significant financial sacrifices and other commitments to make sure their children go to school. Research carried out by Case, Paxson and Ableidinger in 10 sub-Saharan countries found that living with more distant relatives was the main factor in lower orphan enrolment.

Boler and Carroll (2003:50) refer to the multiple disadvantages that orphaned and vulnerable children face as a *spectrum of vulnerability* where a child may find himself in one or more categories of vulnerability. The following table illustrates the spectrum of vulnerability as it relates to education. The spectrum outlines the following: The characteristics of OVCs which can cause

educational disadvantage, the resultant negative impacts of this disadvantage and suggested educational responses:

THE SPECTRUM OF VULNERABILITY WITH REGARD TO EDUCATION

ISSUES OF ORPHANED AND VULNERABLE CHILDREN	CONSEQUENCE FOR EDUCATION	EDUCATION RESPONSE
Poverty	<ul style="list-style-type: none"> • Drop out of school due to unaffordable school fees • Stigmatised due to inadequate uniform and books/stationery • Low attention span because of hunger 	<ul style="list-style-type: none"> • Abolish school fees or provide bursaries • Change policies regarding uniforms & learning materials • School feeding schemes
Stigma	<ul style="list-style-type: none"> • Children affected by HIV/AIDS are socially excluded & marginalised • Negative learning environment • Barriers to participating fully in school activities 	<ul style="list-style-type: none"> • Establish inclusive school policies and practices • Encourage all learners & educators to adopt inclusivity & zero tolerance toward discrimination • Educate community & parents to stand against AIDS-related stigma
Trauma	<ul style="list-style-type: none"> • Special education needs • Struggle to concentrate and learn 	<ul style="list-style-type: none"> • Train educators to identify special needs • Access to counsellors &

		educational psychologists
HIV-Positive	<ul style="list-style-type: none"> • Little expected of these children • Learners & educators fearful of infection • Struggle to adhere to ARV treatment due to lack of understanding 	<ul style="list-style-type: none"> • Create policies, procedures & cultures on inclusive education • Train teachers & learners around infection & universal precautions • Treatment education
Girls	<ul style="list-style-type: none"> • Education is a low priority within family & society • Fear of violence/sexual violence at school • Her labour is needed at home • Sexual risks • Education regarded as irrelevant 	<ul style="list-style-type: none"> • Flexible, certified educational options • Safety to and in school • Female teachers • Evening literacy classes • Providing monetary incentives for girls • Life skills training • Ridding texts and content of gender stereotyping • Gender-sensitive teacher training & school facilities like toilets • Community advocacy
	<ul style="list-style-type: none"> • Depression and anxiety results in low motivation to learn • Silence surrounding death 	<ul style="list-style-type: none"> • Ensure referral & access to bereavement counsellors

Bereavement	leads to emotional problems which in turn impact on learning	<ul style="list-style-type: none"> • Include 'coping with death' as part of school curricula
Lack of family support	<ul style="list-style-type: none"> • Low educational expectations of orphans • Orphans' education have lower priority compared to other children in household • Lack of homework support 	<ul style="list-style-type: none"> • Increase communication between school & home • Establish after-school homework clubs • Create mentor schemes for emotional & intellectual support
Working children	<ul style="list-style-type: none"> • Tiredness during lessons • Inconsistent school attendance • Lower learning achievement 	<ul style="list-style-type: none"> • Provide flexible, sensitive, regulated & certified educational options • Make provision for open & distance learning • Link to broader poverty alleviation strategies & to the development of alternative income generation strategies
Chronic illness	<ul style="list-style-type: none"> • Poor attention • Absenteeism • Struggle to participate in certain school activities like sport 	<ul style="list-style-type: none"> • Ensure that less physically able children are included in each school activity • Train all staff in first aid • Allocate a resource staff member who has knowledge of local health

		care providers
Adult roles	<ul style="list-style-type: none"> • More responsibilities at home allow them less time for education • Education not as important as domestic responsibilities • Young people expect to be treated as adults – leads to discipline problems 	<ul style="list-style-type: none"> • Include more relevant & job-related courses • Give educational support on how to care for sick parents or younger siblings • Inculcate the value of respect between learners & educators & vice versa
Conflict	<ul style="list-style-type: none"> • Denied opportunity to learn • Trauma • Struggle to access schools • Fear of violence affects learning 	<ul style="list-style-type: none"> • Provide education in conflict areas & ensure safety of learners • Give flexible learning options • Train educators to deal with traumatised kids

UNICEF (2006:30) reports that by eliminating school fees countries like Kenya and Uganda have increased school enrolment in general and decreased discrepancies between orphans and non-orphans. Eliminating school fees was made possible through political commitment demonstrated by increases in government and donor spending on education, improved training, professional development and support for teachers, and a strong education policy framework. They make the plea that all governments need to make sure that children have the legal documents that make it possible for them to enrol in school and to receive available support from the government. In addition, governments need to help with finances for uniforms, books and other items; make education more relevant by including life skills into curricula; allowing and encouraging local groups to start community schools and providing school meals.

2.4.3 Psychosocial needs

Furman (1974:12) explains that mourning in children is very different from that in adults. A child finds himself in a unique situation because of the special nature of his ties to his parent(s). Adults distribute their love among several meaningful relationships – their spouse, parents, children, friends, colleagues – as well as their work and hobbies. The child, on the other hand, invests all his feelings in his parents. She states, “Only in childhood can death deprive an individual of so much opportunity to love and to be loved and face him with so difficult a task of adaptation” (Furman 1974:12).

Despite the fact that Erik Erikson does not specifically address the psychosocial needs of orphans, his ego psychological theory serves as a useful model to explain the psychosocial needs of children and youth whose parents have died. Erikson (1963:246) suggests that personality development takes place in eight stages (“The Eight Ages of Man” which he describes as a “list of ego qualities which emerge from critical periods of development”) which range from birth to old age. Each stage is characterised by a developmental crisis which arises from the interaction between genetic development and social influences.

Erikson’s first stage which covers the first year of life is that of *basic trust versus mistrust*. The infant will successfully resolve the crisis of this stage if they are able to develop a healthy trust in the world and themselves and believe that their environment will satisfy their need for food, love and attention - parents obviously play a major role in this regard - and that they are able to meet their needs within their cultural environment. Erikson (1963:247) explains that social trust in the baby is shown through its ease of feeding, the depth of its sleep and the relaxation of its bowels. The baby’s first social achievement is his readiness to allow his mother to leave his presence without too much anxiety or rage, because she has become an “inner certainty” but also an “outer predictability”. The consistency and continuity of the mother’s care gives the infant a basic sense of ego identity. The state of trust Erikson refers to also implies also that the infant is able to trust himself and the capacity of his own organs to cope with urges and that he is able to regard himself as trustworthy enough so that his carers will not need to be on guard in case he gets “nipped” (stolen). There needs to be a healthy balance, however, between trust and mistrust because healthy trust is not blind or naive and needs to be balanced with a measure of distrust which results in caution. If, at the time of a parent’s death, an infant is neglected or left without anyone to care for their needs, the social world will be experienced as threatening and will be approached

with suspicion. Boeree (1997) as quoted in Maqoko (2006:52) warns that children, whose balance tips to the side of mistrust may develop the tendency to withdraw, manifested in conditions such as depression, paranoia and psychosis. Anna Freud (1960) is quoted in Furman (1974:294) stating that very early bereavements followed by very unfavourable life circumstances tend to produce disturbances which may not be treatable – a very concerning statement in the light of the realities of AIDS orphans.

During the second stage, which occurs in late infancy and toddlerhood (1 to 3 years), children, after gaining trust in their caregivers, want to exercise and develop their muscle control (which Erikson [1963:251] believes is a precursor to experimentation with the two sets of social modalities of holding on and letting go) and language which results in self-confidence and *autonomy* if they are successful, or in *shame and doubt* about their abilities if they encounter disapproval, harsh punishment or overprotection from parents or caregivers. Erikson (1963:252) explains that as a toddler's environment encourages him to be more independent, it must protect him from meaningless and arbitrary experiences of shame – which he defined as being completely exposed and conscious of being looked at – and of early doubt. A healthy solution to this crisis is the development of will-power which enables a toddler to make independent choices and practice self-control. Erikson (1963:254) believes that a lasting sense of good will and pride results from a sense of self control without loss of self esteem but conversely a long-term feeling of doubt and shame results from a sense of loss of self-control and of “foreign” over-control. Young (1996:2) states that toddlers need constant reassurance that their adult caregivers will be available when needed. Death of a parent is experienced as a critical loss and leaves the toddler fearful and anxious. Often the death is experienced as absence – the death is understood not by the existence of a parent who is now gone but by the non-existence of a parent who should be there. Maqoko (2006:52) is of the belief that if there is no adequate replacement of the caregiver, the child is likely to regress.

The psychosocial crisis of the third stage, referred to as the play age which occurs between the ages of three to six, is *initiative versus guilt*. At this stage children can act on their own initiative and can therefore feel guilty about what they have done. Erikson (1963:255) explains that the child in this stage has an abundance of surplus energy which allows him to quickly forget about failures and to approach more desirable ends with “undiminished and more accurate direction”. But Erikson warns that the danger of this stage is a sense of guilt over the goals a child has contemplated and the acts he has initiated in his enjoyment of his newly-found physical abilities

and mental power. Children are required to take on the responsibility of their bodies, their behaviour, their toys and their pets which in turn increases their initiative. They sometimes experience uncomfortable guilt feelings, however, when they are irresponsible or are made to feel to feel too anxious. The best outcome of this stage is when a child is able to find the balance between his/her enthusiasm for doing and making things and the inclination to be too self-critical. Young (1996:3) suggests that the egocentric thoughts of children in this stage may cause them to believe that something they did or said caused the death of a loved one. They may use magical thinking to create alternative realities when the world around them is painful. Rando (1988) is quoted in Laverne (2007:2) stating that children in this stage seem to ask many questions about the parental loss and the circumstances around the death and may even exhibit feelings of anxiety and anger toward the deceased. Nagy (1959) is quoted in Corr and Balk (2010:22) suggesting that these children believe that death is reversible i.e. not final.

The fourth stage (referred to either as the school age or the latency years) covers the ages six to twelve. It is the period during which a child has to master the conflict between *industry* and *inferiority*. Children in this stage learn to handle the tools of their culture and society facilitates this process by providing opportunities for learning and co-operation. Erikson (1963:259) observed that in all cultures children in this stage of development get some systematic instruction but it is not always in the kind of school where special teachers have learned how to teach literacy. A healthy outcome of this stage is for the child to develop a sense of competence. Erikson (1963:259) suggests that a child now learns to win recognition by producing things but warns that a child's danger during this stage lies in a sense of inferiority and inadequacy. He writes, "If he despairs of his tools and skills or of his status among his tool partners, he may be discouraged from identification with them and with a section of the tool world". According to Young (1996:4) adults may perceive children's natural need to periodically distance themselves from sadness as having no grief but, just as adults often try to cope with their anxiety through keeping themselves busy, so also the death trauma may have the effect of motivating children to become more industrious. If the death trauma is too severe because of an inappropriate response by significant adults, it may lead to feelings of inferiority. Nagy (1959) in Corr and Balk (2010:27) found that children between the ages of five and nine personify death i.e. they imagine death as a separate person e.g. the grim reaper, a skeleton or a death angel. Maqoko (2006:53) believes that it is really devastating for HIV/AIDS orphans when they are subjected to stigmatisation and isolation by their peer group, community, family members and teachers. It is a huge blow to them to lose the very people (i.e. the parents) who are ideally placed to guide them, to encourage them and to teach them how to

cope with the basics of life. Maqoko (2006:54) states, "Role models who are able to help HIV/AIDS orphans to tip the scales to industry rather than inferiority are sorely needed so that these children can develop competency."

According to Avert[a] (2009:2) children whose parents are HIV positive are commonly subjected to many changes in their lives and start to suffer physical and emotional neglect long before they become orphans. The emotional trauma that results from the death of a parent is seldom addressed and they are left to adjust to a new situation relying on their own resilience often suffering exploitation and abuse during this difficult period.

Avert[a] (2009:2) refers to a study undertaken by Antwine et al. (2005) in rural Uganda which found high levels of psychological distress in AIDS orphans. It was found that anxiety, depression and anger were more common among AIDS orphans than other children. In fact 12% of these orphans stated that they wished they were dead, compared to 3% of other children who were interviewed. These psychological problems are exacerbated when an orphan is separated from his/her siblings. A survey carried out by USAID (2002) in Zambia (cited in Avert[a] 2009:2) revealed that 56% of orphaned children did not live with all their siblings. Furman (1974:22) points out that a child could best undertake the task of mourning when they felt personally safe and could depend on their remaining object relationships, meaning that they could remain with all the surviving family in their own home, that their needs were fulfilled adequately and consistently by the surviving parent or by one continuously available familiar person. This also meant that there were as few changes in the routines of their daily life as possible and that they could count on the support of their loved ones in their struggle with the feelings and facts of their bereavement.

Dane (1994) as quoted in Reyneke-Barnard (2006:52) lists six features of an AIDS death that have an effect on grieving and need to be considered to improve the effectiveness of grief counselling:

- The cultural attitude towards death and the mourning process;
- socially unacceptable death (stigma, fear, discrimination, secrecy);
- the child's relationship with the deceased parent and the availability of a substitute caregiver;
- the child's understanding of death;
- survivor guilt and
- social support.

Wells (1993) in Reyneke-Barnard (2006:53) suggests a number of practical guidelines for helping a grieving child:

- Establish support groups in which to share experiences;
- When informing a child of a death it is preferable that the person emotionally closest to the child, should do it. Hold the child, listen to them and reassure them that it is not their fault. Take their fears seriously and answer questions truthfully.
- Expect that the child may be angry at the bearer of the sad news. Be patient. Do not ask a child to postpone, deny or cover up their feelings.
- Older children may seek self-isolation. Simply be available and give them permission to not be the adult now.
- Try to keep the family's routine going.

2.4.4 The needs of orphaned adolescents

Erikson (1963) as explained by Meyer (1997:218) referred to the fifth developmental stage of adolescence as the period where the young person experiences the psychosocial crisis of *identity* versus *role confusion*. This stage coincides with the beginning of puberty at about twelve and ends with the beginning of early maturity (anywhere between the ages of 18 and 25). A key developmental issue for adolescents is adjusting to physical and sexual maturity (Ruland et al. 2005:4). Together with maturation comes the need to understand relationships, intimacy and peer pressure. It is also developmentally appropriate for adolescents to challenge rules, testing cultural values, finding a means of economic support and 'trying out' risky behaviours. Erikson (1963:261) explains that adolescents, in their search for a new sense of continuity and sameness, have to refight many of the battles of previous years, even though they must artificially choose "innocent" people to play the roles of opponents; and they are always ready to follow the lead of idols and ideals as "guardians of a final identity". Erikson (1963:262) warns that the danger of this stage is role confusion and that delinquent and psychotic episodes are not uncommon in adolescents. A key protective factor, however, linked to positive outcomes for young people is connectedness to parents, including parents' expectations with regard to completing school. A positive outcome is avoiding risky sexual behaviour. Orphans, however, are commonly subjected to psychosocial and economic pressures which can increase the likelihood of these risky behaviours. In the absence of the protective factor of having parents, adolescent orphans are more vulnerable to HIV and other sexually transmitted infections themselves.

According to Ruland et al. (2005:5) adolescence involves developing toward economic and social independence, including exploring career options and secondary education. Going to high school, however, involves more challenges for adolescents who must pay their own fees or help support a family. Orphaned adolescents often have more challenges which include becoming household caretakers or breadwinners. The problem is exacerbated by high unemployment rates and lack of secondary or vocational schooling opportunities.

The drain that HIV/AIDS has on the finances of households often place adolescents' chances of staying in school at risk especially if they have to take on new responsibilities for supporting the family, according to Children on the Brink (2004) in Ruland et al. (2005:5). Struggling to cope financially also deprives many adolescents of much needed recreation and participation in community activities. These circumstances are often triggering factors to depression, hopelessness and risky behaviour.

According to Nagy (1959) as quoted in Corr and Balk (2010:26), adolescents understand that death is both final and universal. Berger, 2001; Longress (2000); Anderson et al. (1999) as quoted in Laverne (2007:2) characterize adolescent understanding and meaning of death as one of "frightening shock and in-depth spiritual examination".

It is usual for them to experience emotions of anger, resentment, hopelessness and depression but losing a parent or close family intensify these feelings and in turn can lead to a sense of alienation, desperation and withdrawal and ultimately to vulnerability to HIV, according to Children on the Brink (2004) in Ruland et al. (2005:5). Berger et al. as quoted in Laverne (2007:2) concur with this stating that since the adolescent is attempting to find his/her identity and that the parent is a role modelling figure who is able to help with guiding and encouraging this process, it is not surprising that an adolescent may feel powerless, helpless, dependent and even angry due to the death of their parental figure.

Ruland et al. (2005:2) therefore suggest that the kinds of help that adolescent orphans need is different from that needed by children. This is because their needs are more complex due to their physical and psychological development during puberty and the steps that are needed to develop toward independence and adulthood. An estimated 55% of all orphans worldwide under the age of 18 are adolescents between the ages of 12-17. Despite this fact, most programmes do not focus on the distinct needs of adolescents like secondary education, vocational training, sexual and

reproductive health education and services, psychological and social support for the difficult transition to adulthood, and mentors as role models.

2.5 CHARACTERISTICS OF GRANDPARENT-HEADED HOUSEHOLDS

The family has been regarded by many as a system. According to Von Bertalanffy's (1950; 1974) as quoted in Moore (1997:557) general system theory, systems contain smaller elements (subsystems) but also form part of larger systems (supra-systems). Therefore an individual in the family, for example the grandparent or the grandchild, make up the subsystem of the larger family system and the grandparent-headed family is itself part of the supra-system of the community.

Parsons (1951) as quoted in Toseland and Rivas (2005:56) also described groups (such as families) as social systems with many interdependent members trying to maintain order and a stable equilibrium while they operate as a unified whole. Groups/families must utilise their resources and act to meet changing demands if they are to survive. According to Parsons et al. (1953) as quoted in Toseland and Rivas (2005:56) systems have four important tasks:

1. *Integration* – making sure that the members of the group fit together.
2. *Adaptation* – making sure that the group/family changes to cope with the demands of its environment.
3. *Pattern maintenance* – making sure that the group/family defines and keeps its basic purpose, identity and procedures going.
4. *Goal attainment* – making sure that the group pursues and achieves its tasks.

In order to remain in equilibrium, the group must accomplish these four functional tasks.

As mentioned, a family forms part of the supra-system and is therefore influenced by it. For example, the way a family deals with the death of a parent will be influenced by the culture, religion, socioeconomic status and values that prevail in the society within which the family exists. In Laverne (2007:4), Kalish (1977) is quoted explaining that in modernized society, a parent is blamed for creating internal processes that led to his/her own death (for example smoking, poor eating habits, unprotected sex et cetera) In other cultures, especially isolated societies, the death is attributed to external agents like evil spirits or magic.

The family, in turn, also impacts on the supra-system in that the supra-system has to adjust and provide for the changing needs and circumstances of the family system. For example, a government welfare programme needs to cater for the financial needs of grandparents – who are no longer economically active – caring for orphaned children.

2.5.1 United States of America

Park (2005:19) states that the presence of grandparents in their grandchildren's lives is now more common and lasts longer than ever before. For example, in 1900, most grandchildren did not know their grandparents; in 2000, the likelihood that a 20-year old had at least one living grandparent was more than 96%. It is not uncommon for women to be grandmothers for more than forty years.

According to the United States Census Bureau (1998) as quoted in Park (2005:19) there were four million children under the age of 18 (or 5,5% of children) living in grandparent-headed households in the United States in 1997. The fastest-growing type of grandparent-headed household, since 1990, has been the one in which grandparents and their grandchildren live together in the absence of the grandchild's parents, referred to as "skipped-generation" households and over 90% of these children are cared for on an informal basis i.e. the arrangements have been made privately at the initiative of the child, their parents or other person. By 2000, roughly 2,4 million grandparents were providing most of their grandchildren's basic needs (Park 2005:19).

Fuller-Thomson et al. (1997) are quoted in Minkler and Chehimi (2003:5) stating that the average age of grandparent caregivers in the United States is 59,3 and more than half are aged 60 and above. A typical grandparent caregiver is a white married woman living a modest lifestyle but above the poverty line. Seventy-three percent of grandparent caregivers in California are married and sixty-two percent are women. More than half (53%) are still in formal employment and a considerable number (16%) are poor. Being single, poor and African American significantly increases the chances of becoming a caregiver for one's grandchildren according to Casper et al. as quoted in Minkler and Chehimi (2003:5). In California, 12% of all African-American children, 11% of Hawaiian and Pacific Islander children, 10% of Native American children and 7-8% of Hispanic, mixed race children live in grandparent headed households according to the US Census (2001) as quoted in Minkler and Chehimi (2003: 6).

Fuller-Thomson et al. (1997) are quoted in Minkler and Chehimi (2003:5) stating that 72% of all children who come into the care of a grandparent, notwithstanding their race, class, region etc. are

infants or preschoolers who obviously need a more intensive level of care. In California more than one third of grandparent caregivers are exclusively responsible for childcare for five years or longer. Almost one-third of grandmother caregivers suffer from depression and more than half have at least one limitation in an activity of daily living such as caring for personal needs, climbing a flight of stairs or walking six blocks.

One of the main reasons for American grandparents becoming the guardians of their grandchildren, according to Burnette (1997) and Feig (1990) in Minkler and Chehimi (2003:7) is substance abuse, particularly the cocaine habit, amongst parents. The National Institute of Drug Abuse (1997) in Minkler and Chehimi (2003:7) reports that approximately 15% of American women between the ages of 15-44 are substance abusers and almost 40% of these women have children living with them. Burton (1992) and Minkler and Roe (1992) in Minkler and Chehimi (2003:7) suggest that grandparents who become the primary caregivers of their grandchildren because of their children's substance abuse are prone to suffering special emotional consequences due to the shame, fear and uncertainty about the future. According to Minkler and Chehimi (2003:8), other social factors responsible for the increase in grandparent headed households are divorce, teen pregnancy, the rapid growth in single parent households and the HIV/AIDS epidemic (which had claimed the lives of the mothers of approximately 125 000 to 150 000 American children and youth by the year 2000). More than half of the children of mothers who are in prison in the United States live in grandparent headed households (Department of Justice, 1997 in Minkler and Chehimi (2003:8).

Park (2005:23) states that according to her investigation of the economic well-being of families headed by grandmothers, single grandmothers showed the highest level of disadvantage compared to married grandmothers. They were less likely to have completed high school education compared to other types of families and were also more likely to have the lowest family incomes and to have poor health. Interestingly, they were more likely ever to have married than those living in three-generation households.

In the United States, many grandparent caregivers receive financial aid from the state under a scheme called "Temporary Assistance for Needy Families (TANF). The regulations of TANF, however, are potentially disadvantageous to grandparent primary caregivers – particularly those who live near or below the poverty line – because they are treated like other caretakers in that they have to find employment after two years of receiving assistance and are subject to time limits for

aid. But for obvious reasons some grandparent primary caregivers may be less able to go back to work than younger parents and are likely to be regarded as “obsolete” by potential employers and may also be dealing with ageing issues or deteriorating physical health (Park 2005:19).

2.5.2 Australia

Mission Australia (2007:1) reports that more and more grandparents across Australia are raising their grandchildren with the parent/s either temporarily or permanently being unable to care for their children. The reasons for grandparents raising their grandchildren are reportedly: the death of a parent, parental substance abuse (e.g. in Victoria 52% of grandparent caregivers surveyed had children who were abusing substances), imprisonment, mental health issues, child neglect and/or abuse, unemployment, poverty and domestic violence. A child living permanently with their grandparents is not always due to family breakdown or parental problems because in Australia this phenomenon may simply be a cultural norm. Among Aboriginal Australians, for example, it can be that when the parent/parents decide to move to the city they might leave young children with their grandparents.

According to the Australian Bureau of Statistics' 2003 Family Characteristics Survey as quoted in Mission Australia (2007:1), there were estimated to be 22 500 grandparent headed households in Australia. These grandparents looked after 31 100 children between the ages of 0-17 years.

Data from this survey in Australia revealed the following characteristics of grandparent-headed families:

- In 61% of the households, the youngest grandparent was aged 55 years and older;
- Approximately two-thirds were dependent on government pension, benefit or allowance as their main income source but a significant proportion (>80%) of grandparents aged 65 years and over lived in their own homes where the mortgage had been paid off;
- Almost half (47%) were single grandparent families with 93% of single grandparents being grandmothers;
- One third shared their home with one or more other adults (usually a relative of the grandparent) as did a quarter of couple grandparent families;
- In most households the youngest child was between 5 and 14 years;
- Approximately one tenth of the grandparents had three or more children in their care;

- A similar proportion of grandparent headed families lived in major cities as lived in rural areas (48% compared to 45%) which is noticeably different from other families (65% compared to 33%);
- 92% of children in these families had a natural parent living somewhere else and over a third (37%) had face to face contact with a parent fortnightly or more frequently.

2.5.3 Sub-Saharan Africa

The following newspaper article which appeared in the Sunday Argus (November 27, p.26) quoted in Ferreira (2007:24) clearly depicts the circumstances of a grandparent headed household in South Africa:

“Numerous poor older South Africans who are eligible to receive a social pension or a grant for eligible minors for whom they care encounter bureaucratic obstacles and irregularities when trying to access grants. Mrs Shikisha Mkhize is one such elder. She does not know when she was born but estimates that she is in her late seventies; she lacks official documentation required in order to apply for a grant. Mkhize and three teenage grandchildren live in abject poverty in the Mboza community in northern Kwazulu-Natal. Often they do not eat at night if there is no food; sometimes they go three nights without supper. Mkhize’s daughter died of AIDS related illness soon after the daughter’s husband died in the same way. She has struggled since to look after her grandchildren and has been working long hours tilling and planting fields to make ends meet. On average, she earns less than R11 a day. When asked how her husband and son-in-law had died, she said people in the area had used witchcraft on them. She had been told that they had died from AIDS but she did not want to believe or talk about it. Her biggest problem, she states, is that she cannot get a state pension because she lacks an identity document. Her attempts to apply for child support and foster care grants for her grandchildren have been to no avail. “I don’t have any documentation of my daughter’s death or my grandchildren’s birth. I have tried many times to get grants and my pension, but it will never happen unless I bribe certain officials,” she says. “If I could get some money from grants, my grandchildren could survive and we’d have hope for a better life.”

Mrs Mkhize’s circumstances overlap in many respects with the characteristics of grandparent headed households in sub-Saharan Africa.

The fact that the household is headed by a woman is no surprise. UNICEF (2003:22) report that households headed by women are more likely to take responsibility for orphans – not only their

own children but are also more prepared to take care of other orphans. For example, in 2002 approximately 48% of children in Namibia and 32% of children in Kenya who lost their mother were living in female headed households. Zimmer and Dayton (2003:14) confirm this fact by stating that women are much more likely than men to live in extended households (almost 70% of women versus about 43% of men). The reasons they offer for this fact are firstly that women tend to live longer than men (in sub-Saharan Africa there are currently 100 older women for every 86 older men, according to HelpAge International [2002] as quoted in Van Dullemen [2006:101]) and may therefore have more grandchildren and in-law children with whom to live; secondly, when the husband dies, a woman may need to move in with extended family for support; thirdly, grandmothers, rather than grandfathers, are seen as the more natural choice of individuals to assist in caring for grandchildren.

Schenk et al. (2007:9) using data from the U.S. funded “RAPIDS” (Reaching AIDS-affected People with Integrated Development and Support) household survey conducted in 2005 across six sites in Zambia, found that while female-headed households comprised only 24% of all households in the survey, in every study site they were disproportionately represented among the households with one adult. This pattern reflects the fact that widows take on household responsibility after the death of their husband. They also found that female household heads were generally older than their male counterparts – in fact 23% of female household heads were aged 60 and above, compared to 14% of male household heads.

Mrs Mkhize’s circumstances of poverty are also typical of many grandparent headed households in sub-Saharan Africa. Deininger et al. (2003) are quoted in Miller et al. (2006:3) stating that households living in extreme poverty, such as those headed by nonworking and elderly grandparents, lack the resources to adequately care for orphans. Booyesen (2003) is quoted in UN DESA (2007:41) finding that households in South Africa that had experienced illness or death in the recent past were more than twice as likely to be poor than non-affected households, and they were more likely to experience long-term poverty. Floyd et al. (2007:789) found that children of HIV-positive parents who were living in grandparent headed households were, on average, living in households with fewer household assets than children of HIV-negative parents. This added to the fact that grandparents may be physically frail, less economically active than younger people, the death of their son/daughter may have resulted in a loss of financial support, and they may be the guardians to grandchildren from more than one son or daughter, could mean that they were more vulnerable than other households. According to Andrews et al. (2006:273) households with

orphans are more likely to be poor. UNICEF (2003:17) attributes this fact to the increased dependency ratio, meaning that in these households the income of fewer adults earning a living is sustaining more dependants.

The fact that Mrs Mkhize spends much time tilling and planting fields is also typical of households with orphans in sub-Saharan Africa. UNICEF (2003:19) refers to a United Nations Food and Agricultural Organization study in Uganda which found that widows were working two to four hours more each day to make up for the reduction in labour and income resulting from their husband's death. Other strategies used in an effort to make ends meet include eating less (which Mrs Mkhize and her household could attest to), selling household goods, land or other assets and borrowing from extended family and friends. UNICEF (2003:19) cautions that these strategies are not sustainable and in fact intensify the vulnerability of both adults and children. Mutangadura (2001:3), quoting from Neema (1999) and Quisumbing et al. (1998) states that women play a major role in agricultural production in rural Africa accounting for 70% to 80% of the food.

The newspaper article referred to above does not indicate the gender of the teenage orphans. Evans (2005:10), however, reports that boy orphans are much more likely than girl orphans to stay with grandparents (29% versus 23%, significant at 95% confidence level), whereas girl orphans are more likely to stay with other relatives (45% versus 38%, significant at 99% confidence level). The explanation given is that girls are more useful for household labour and that more distant relatives would expect more compensation in labour than grandparents, who are more concerned about the orphan's best interest.

Mrs Mkhize's scenario of caring for teenagers may be different from many in that Evans (2005:11) indicates that older orphans (older than 8 years) are much more likely than younger orphans to stay with non-relatives (8% versus 2%, significant at 99% confidence level) and are much less likely to stay with grandparents (22% versus 34%, significant at 99% confidence level). Evans's rationale is that non-relatives may be mainly interested in taking in orphans who will be of greater use in the short term, whereas grandparents may be more prepared to make short-term sacrifices for the longer term well-being of the child either because their closer relationship increases their likelihood of reaping benefits in the long-term or because of greater generosity towards the orphan.

Having three double-orphans to care for also appears to be a rather unique situation. Zimmer and Dayton (2003:24) show that in 15 countries of sub-Saharan Africa 1,7% of older adults live with at least one double-orphaned grandchild. Approximately 4% of those living with grandchildren live

with at least one double-orphaned grandchild across the whole region. In Zimbabwe and Uganda, however, nearly 5% of all older adults live in a household with at least one double-orphan present. About one-third of households with double-orphans have two double-orphans, but rarely are there more than two. In the three countries with very high HIV/AIDS related mortality rates viz. Uganda, Zambia and Zimbabwe, about half of the households with double-orphans have more than one double-orphan present.

Zimmer and Dayton (2003:22) mention that in countries with high HIV/AIDS rates many grandchildren live with older adults because their parents live elsewhere or because their parents have passed away – as in the case of Mrs Mkhize's grandchildren. Freeman and Nkomo (2006:3040) mention that 29,3% of respondents in their study indicated that the main reason why children were staying with non-biological parents was that the mother/father had died and 29,5% of these respondents reported that HIV/AIDS was the cause of death of the parents. The high and increasing rates of orphans (due to the HIV/AIDS pandemic) could be the catalyst to changes in family living arrangements and especially contributing to the phenomenon of many households that consist of only the older grandparent generation (older than 60 years) and the generation under 15, with no members of the middle generation (Zimmer and Dayton 2003:9). Save the Children [UK] (2007:2) points out that the culture and social norms within different countries determine who is likely to look after kin. Participants in the RAPIDS household survey in Zambia referred to earlier described how the responsibility of caring for children after the death of their parents should fall to the child's extended family, most often children's grandmothers (Schenk et al. 2007:15). Evans (downloaded 23 June 2010) suggests that the tendency of orphans to stay with grandparents can be explained by the kin selection hypothesis in that a child shares the most genes with her grandparents and siblings, followed by other relatives. Mutangadura (2000:11) found that, like Mrs Mkhize, most grandparents (65%) in Zimbabwe who foster their grandchildren were maternal grandparents.

The fact that Mrs Mkhize does not know her birth date could indicate a low level of education. Evans (2005:10) indicates that orphans are likely to go to households where the household head has, on average, 0,5 years less schooling and explains that this may be because a large proportion of orphans stay with grandparents who on average have less education. Zimmer and Dayton (2003:14) found that across 16 countries in sub-Saharan Africa, 16,1% of women and 37,9% of men (aged 60 and older) had some schooling. Levels of schooling are, in the main, higher in East Africa than in West Africa. Ferreira et al. (2007:12) found in their survey of 55

“contributive” elders in the Western Cape (of whom 69,1% were responsible for raising grandchildren), that 12,8% had no formal schooling, 16,4% had less than 6 years of schooling, 21,8% had between 6-7 years of schooling, 29,1% had between 8-9 years of schooling, 14,5% had between 10-11 years of schooling, 3,6% had matriculated and 1,8% had post matric education. Madoerin (2006, downloaded 30 June 2009) also mentions that most of the grannies in the Kwa Wazee project – a program in Tanzania for and with grannies who take care of their grandchildren – are illiterate.

UNICEF (2003:43) states that children whose births are not registered are at risk of not having access to many of their rights – Mrs Mkhize’s grandchildren share these risks with more than 66% of children in sub-Saharan Africa whose births went unregistered in 2000. There is evidently a high correlation between low levels of birth registration and countries badly affected by HIV/AIDS: 10% of births in Zambia, 6% in the United Republic of Tanzania and only 4% in Uganda are registered. Weaknesses in registration systems also bring about the scenario where deaths are not registered. Mrs Mkhize experienced first-hand the ramifications of unregistered births in that she was unable to access financial support from the Department of Social Development for this reason. Miller et al. (2006:5) found that only 34% of orphan households in their Botswana Family Health Needs Study received caregiving support from the government. UNICEF (2003:35) report a similar figure stating that surveys in urban areas of Zambia revealed that only around one third of households with orphans were receiving any type of support , but from relatives and friends – not from the government. Save the Children [UK] (2007:4) report that in Rwanda, only 0,2 % of households hosting orphans receive a full package of care and support (including financial and psychosocial support as well as access to health and education services).

Save the Children [UK] (2007:4) suggest the following common issues for carers of HIV/AIDS orphans who would obviously include grandparents caring for their grandchildren:

- The overall burden, particularly when caring for disabled children;
- a lack of time due to both parents working;
- the behavioural problems presented by children;
- an increasing number of children to care for, with the support system – usually provided by the extended family – getting smaller;
- the stigma that goes with children orphaned by AIDS;
- a lack of space in the home;

- conflict in the family over where the child/children should be placed, e.g., where the child's placement is without the permission of his/her birth parents or the child is born out of wedlock;
- lack of parenting and child communication skills;
- assuming that the responsibility to care for someone else's child will be a long-term responsibility;
- the impact on the carer's health, particularly for grandparents and older carers.

With regard to the carer's health, Ferreira (2007:22) found that self-rated poor health reduces elders' involvement in responsibility for grandchildren but that elders continue to care for grandchildren in spite of physical limitations. Some of the limitations mentioned include: pain in their legs, forgetfulness, paralysis, general weakness, poor balance, stiff joints, headaches and tiredness (Ferreira et al. 2007:20). Ferreira (2007:22) also mentions that elders who raise, or help to raise grandchildren are often depressed.

2.6 PREVALENCE OF ORGANISATIONS LENDING SUPPORT TO GRANDPARENT-HEADED HOUSEHOLDS

It appears that in first world countries like the United States there is an abundance of organisations which help grandparents who raise grandchildren to manage their responsibilities. The American Association of Retired Persons [AARP] (2008:1), for example, has an internet based Grandparent Information Centre which offers resources for grandparents of all types and in particular lists support groups for grandparents raising grandchildren. It offers a sophisticated, yet user-friendly resource where a grandparent, who obviously has access to the internet, simply types in his/her state and city on the AARP Foundation "Grandcare Support Locator" and a list of organisations and agencies in that vicinity with all their details are listed. The grandparent indicates whether he/she requires a telephone support group, an in-person support group or an on-line support group. I conducted an on-line search, for example, of in-person support groups in the city of Greenville in the state of Michigan and discovered that there were nine agencies that were available to grandparents, some of which were also national organizations. They included organizations like: *Family, Friends and Neighbours; Kinship Care Resource Center – School of Social Work- Michigan State University; Grandfamilies of America; Grandparents Parenting Association* and *Grandparents R Us*.

Evidently America's first public housing scheme for grandparents raising their grandchildren is being constructed in the city of Boston. It will be called "Grandfamilies House" and will consist of 26 apartments which will be handicapped accessible for the elders and toddler-proofed for younger children. Developers of this \$4 million housing complex stated that it would offer a support network for families struggling with some very different generational needs. Residents will pay rent which is equal to 30% of their family income which for some could be as much as \$375 per month. The YMCA will run programmes at this centre which will teach everything from computers to aerobics to both age groups.

Other national support groups in the United States for grandparents include: Generations United, Grandparents Raising Grandchildren, GAP [Grandparents As Parents] and ROCKing [Raising Our Children's Kids] (AARP 2008:4).

I also came across an organization in New Zealand called *Grandparents Raising Grandchildren Trust NZ* which was founded in 1999 by Diane Vivian to provide support to grandparents who are primary caregivers to grandchildren. There are currently over 49 support groups throughout the country which function under the auspices of this organisation (Grandparents Raising Grandchildren Trust NZ 2009:1).

The situation in South Africa with regard to support for grandparents who are the primary caregivers to their grandchildren appears to be quite different from first world nations like The United States of America and New Zealand. Firstly, it would be very difficult to enumerate the number of organizations in South Africa lending support to grandparent caregivers as there does not appear to be a national umbrella body for these organisations which could possibly provide a data base. As recently as May 2010, however, a truly historic event took place in Manzini, Swaziland, where five hundred grandmothers from across sub-Saharan Africa came together for the first international Grandmothers' Gathering on the continent. The purpose of the Gathering was to bring the world's attention to grandmothers' need for more support and to recognise their vital leadership role in 'resuscitating' families and communities severely affected by the AIDS pandemic (Stephen Lewis Foundation 2010:1). In my view the Stephen Lewis Foundation, which organised the event, has the potential of becoming an umbrella body for all the isolated support groups for grandparents in sub-Saharan Africa.

My research on the World Wide Web reveals that the organisations that do offer this service are smaller non-government organisations which receive funding from first world countries for AIDS-

related projects. They are generally situated in the larger townships within the metropolitan areas of the country and provide a wide range of services which include support groups for grandparents, mainly grandmothers. I have personally contacted at least three of these organisations and each was unaware of other organisations providing a similar service.

The most prominent organisation in the Western Cape offering support to grandmothers is “Grandmothers Against Poverty and AIDS [GAPA] which operates out of Khayelitsha. Each month workshops which include topics such as vegetable gardening, human rights, bereavement counselling, elder abuse, accessing social grants, drawing up a will and business skills are held for grandmothers. Grandmothers are also invited to attend weekly support groups which are held in the homes of area representatives. There are presently twenty five psychosocial support groups in Khayelitsha and Gugulethu which cater for 294 grandmothers caring for their grandchildren. GAPA has expanded its operation to the Eastern Cape where six psychosocial groups meet on a weekly basis in the Tsolo district. GAPA membership is limited to grandmothers who are 50 years and older and who have been affected by HIV/AIDS in some way (GAPA 2010:1).

A similar project in Port Elizabeth, a registered NPO called the GoGo Trust provides care and support for widows and orphans living in townships in Port Elizabeth and operates using a Christian world view. The aims of the GoGo Trust are:

- To gather the gogos of Kwazakhele and neighbouring townships together for encouragement and support and help the gogos to facilitate care for orphans living in their own families and surrounding communities;
- to provide physical, spiritual, emotional and educational support to orphans living in granny headed households, aunt headed households and child headed households and
- to expand the income generating projects initiated by the gogos viz. two sewing projects and a bead workshop run by the gogos.

Every Tuesday widows who are leaders in their communities and local churches come together for encouragement and teaching with regard to caring for orphans and includes topics like financial management and leadership training. The gogos are served a nutritious meal during this meeting and given bread to take home for their grandchildren. The ladies who attend this group each have a “soup cell” which they run in their homes throughout the week. There are currently 10 “soup cells” which reach more than 300 people a week in Kwazakhele and surrounding communities (Frood 2008:2).

In Alexandra Township, Gauteng, a group of grandmothers called the Go-Go Grannies help and encourage each other as they raise their orphaned grandchildren. This group of grannies form part of the Alexandra AIDS Orphans Project, which runs support group programmes for children and caregivers living with, and affected by, the pandemic. The project provides psychosocial, financial and material support – in the form of one-time building grants, seeds and fertilizers – to 30 grandmothers. In fact a film called, “The Great Granny Revolution” which documents this group’s relationship with a group of grandmothers in Wakefield, Quebec, in Canada was produced in 2007. The Canadian group of grandmothers provide emotional and financial support to the Go-Go Grannies in Alexandra (Giving and Sharing Foundation 2008:1).

One programme with a national presence is the “goGogetters” which is a project run under the banner of Lovelife. Through the goGogetter model which deploys grandmothers to individually support 10-20 orphaned and vulnerable children. According to the pamphlet, *Oudtshoorn’s Granny Focus Support Group: Activities 2009/10*, the project aims to:

- Ensure that each young person attends and completes school;
- improve their access to food;
- ensure that they access the social security grants to which they may be entitled;
- trying to prevent them from being sexually, physically or emotionally abused;
- Talking to young people about their aspirations, HIV, relationships, sex and sexuality (facilitating a sense of belonging, future-perspective and personal development).

These grandmothers, in turn, receive support in the form of support groups which meet on a regular basis. The aims of goGogetter support groups are to:

- Share solutions to OVC problems;
- share information
- engage in problem solving together;
- listening to and empathising with each other;
- getting emotional support, guidance and counselling from the group facilitator (often a trained psychologist);
- getting specialised information from the support group guest.

Loveline has also initiated a national toll free helpline for the grandmothers which offers counselling services for the granny herself or with regards to problems related to an OVC and helps with enquiries related to OVC support. In speaking to the local co-ordinator, I learned that there are six support groups in the Eastern Cape alone (2010, pers. comm. 12 February 2010).

2.7 CONCLUSION

The main aim of this chapter was to conduct a literature study of the phenomenon of grandparents fulfilling the role of parents in the context of the HIV/AIDS pandemic. The alarming statistics regarding the pandemic revealed that sub-Saharan Africa is experiencing a disproportionate crisis which calls for immediate and sustained support from the international community. It also became evident that, despite the fact that grandparents are playing a vital role in providing care to millions of orphaned grandchildren, that this may not be a long-term solution to the orphan crisis in Africa. The fact that the resources of African grandparents' are currently stretched beyond their limit could indicate that they are unable to adequately provide for the multi-faceted needs of orphaned children and adolescents.

The following chapter will outline the research design of my empirical study of grandparent-headed households in order to explore and describe their experiences and needs.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

In chapter two of this research report, the findings of my literature study of the HIV/AIDS pandemic and the resultant phenomenon of grandparent-headed households were described. The literature study also focused on the needs of orphaned children and adolescents. Chapter three describes the research methodology that was used in my empirical study of grandparent-headed households.

Thomas (2009:70) is of the opinion that the chapter on research methodology should be more than the presentation of the method one used in one's research and should be a discussion of the methods that were used and, more importantly, why they were used. The research design, according to Thomas (2009:70), is the plan for the research and needs to take the researcher's expectations and his/her context into account.

The goal of my empirical study was to explore the experiences of grandparent-headed households with a view to establishing the needs of the individuals/subsystems within the family system as well as the system itself and to translate this data into guidelines for professionals and lay people who provide support to these families. I chose the qualitative orientation to conducting my research as I believed it would serve me well as I was working with what Neuman (2006:151) referred to as *soft data* i.e. impressions, words, sentences, symbols et cetera as opposed to numbers which Neuman (2006:151) would classify as *hard data* (for which the quantitative orientation would be more appropriate). Lichtman (2010:5) defines qualitative research as, "a way of knowing in which a researcher gathers, organizes, and interprets information obtained from humans using his or her eyes and ears as filters. It often involves in-depth interviews and/or observations of humans in natural and social settings." Tutty, Rothery and Grinnell (1996:4) define qualitative research as the study of people in their natural habitat as they go about their daily business. Holloway and Wheeler (1998:4) suggest that qualitative researchers adopt a person-centred and holistic perspective in order to gain a deeper understanding of human experiences. According to Neuman (2006:151) they try to provide true interpretations that take specific social-historical contexts into account. Berg (1995:6) argues that one does not conduct research for the sole purpose of gathering data, but to discover answers to questions by examining various social settings and the individuals who live in those settings.

A number of traditional methodologies for qualitative research are available to the researcher. According to Cooper and Endacott (2007:2) they are broadly classified as *interpretive* or *critical*. *Interpretive* approaches set out to describe and understand a phenomenon and the methodology

chosen is determined by the emphasis. Ary et al. (2006:456) highlight seven types of interpretive qualitative research viz. case studies, ethnographic studies, phenomenological studies, grounded theory studies, basic interpretive studies, content or document analysis, and historical studies. *Critical* approaches like action research and feminist research emphasize change or emancipation and participants play an important role in the design and implementation of the study, according to Cooper and Endacott (2007:2).

For my empirical study I chose an interpretive approach known as the *generic* qualitative method. Caelli, Ray and Mill (2003:2) describe a generic qualitative approach as studies that “seek to discover and understand a phenomenon, a process, or the perspectives and world views of the people involved”. Ary et al. (2006: 463) refer to this method as basic interpretive studies. According to Caelli et al. (2003:2) other terms used to define the *generic* qualitative research method are: non-categorical qualitative research approach and basic or fundamental qualitative description. These types of study do not fall neatly into any of the traditional methodological categories such as grounded theory or phenomenology. I decided to use this approach because my research study was one of limited scope and I felt that it was not prudent to engage in a deeply theoretical and methodologically sophisticated study.

The research problem of this study is: *What guidelines are necessary for empowering grandparents who fulfil the role of parents in the context of the HIV/AIDS pandemic?*

In my attempt to answer the above-mentioned research problem, the following sub-problems were addressed in this empirical study:

- What are the needs of orphaned children?
- What are the characteristics of grandparent-headed households?
- What helping services are presently in place for grandparent-headed households?
- What are the views and experiences of two grandparent-headed households?
- What are the views of two groups of stakeholders with regard to the phenomenon of grandparent-headed households?
- What are the guidelines for professionals and lay people who endeavour to empower grandparents fulfilling the role as parents in the context of the HIV/AIDS pandemic?

The above-mentioned list of sub-problems excludes the following sub-problems which were addressed in the literature study in the previous chapter:

- What is the prevalence of HIV/AIDS?
- What is the prevalence of grandparents assuming the role of parents to their grandchildren?
- How can Erikson's model of psychosocial development be applied to this problem?

For the purposes of this study I chose to conduct three separate focus groups and three case studies. I facilitated a focus group with a group of grandmothers caring for their orphaned grandchildren, a group of stakeholders and a group of orphans living in grandparent-headed households. The case studies highlighted the views and circumstances of two grandparent-headed households as well as an NGO in Cape Town serving grandparents who take care of their orphaned grandchildren.

3.2 FOCUS GROUPS

McMillan & Schumacher (2001:455) define the focus group interview as a strategy for gaining a deeper understanding of a problem or an assessment of a problem, concern, new product, programme or idea by interviewing a group of people (who have been purposefully sampled) rather than each person individually. Neuman (2006:412) suggests that the focus group is a special qualitative research technique in which people are informally "interviewed" in a group-discussion setting. He adds that this type of research has grown rapidly in the past twenty years, but according to Toseland and Rivas (2005:358) focus groups were used as early as World War II to examine the effectiveness of wartime propaganda.

Toseland & Rivas (2005:358) explain that focus group meetings consist of a semi-structured interview and discussion with 6 to 12 group members facilitated by a moderator. The moderator is trained to be nondirective and to facilitate free, open discussion by all group members ensuring that no single member dominates the discussion. They would probe superficial answers and encourage the group to move on when a particular topic has been adequately covered.

3.2.1 Motivation for the use of a focus group interview

My rationale for using the focus group was that this form of interviewing facilitates natural and spontaneous dialogue around a phenomenon which all the participants could identify with and would assist me in acquiring relevant data pertaining to the experiences, feelings and needs of the participants. I also believed that I would gain a larger amount of data in a shorter space of time compared to using one-on-one interviews. My decision to hold three separate focus groups was based on my need to learn about the phenomenon of grandparent-headed households from the unique perspective of each of the three groups namely the grandparents, stakeholders and orphans. By grouping the participants in this

way I believed that I would elicit more data from as they would feel more secure in each other's company hearing their peers expressing similar opinions and feelings. With regard to the stakeholders group I predicted that the level of dialogue would be more advanced than the other two groups and would potentially side-line the other participants had I included them in the same focus group.

3.2.2 Data collection

The following table depicts how I conducted the focus group interviews:

METHODOLOGY USED IN FOCUS GROUP INTERVIEWS

STEPS	DESCRIPTION
1.Preparation	<ul style="list-style-type: none"> • Prepared consent forms • Identified key person to source participants. • Ensured that recording equipment was in working order. • Identified a person to serve as translator. • Purchased refreshments for three focus group sessions.
2.Select the participants for each focus group	<ul style="list-style-type: none"> • Identified the three separate groups that should be represented. • Identified the selection criteria for participants ensuring that each group was homogenous. • Using purposive sampling (specifically <i>snowball sampling</i>) set wheels in motion to 'recruit' participants for each focus group. • Sent out consent forms to be signed by participants.
3.Decide on timing and location	<ul style="list-style-type: none"> • Planned for each session to last between one-two hours. • Confirmed a convenient location for participants of the focus groups • Ensured that there was adequate privacy and minimal noise. • Confirmed the date and time of each session. • Ensured that the necessary information regarding venue/time was conveyed to participants.
4.Prepare the discussion guide	<ul style="list-style-type: none"> • Prepared an outline to serve as a framework for myself as facilitator • Referred to sub-problems and literature study.

	<ul style="list-style-type: none"> • See appendices #3,4,5
5. Conduct the interview	<ul style="list-style-type: none"> • Collected the consent forms before starting. • Introduced myself and got participants to introduce themselves. • Established rapport with group. • Explained the purpose and form of discussion. • Set group at ease. • Established a few ground rules e.g. everyone to participate • Welcomed divergent views • Made provision for translation • Controlled the discussion. • Thanked everyone for participation. • Refreshments were served.
6. Record the discussion	<ul style="list-style-type: none"> • Recorded proceedings using audio recorder. • Made notes. • Transcribed the recordings.
7. Analyse the results	<ul style="list-style-type: none"> • Analysed the data using method proposed by Ary et al. (2006:490)

In each focus group I recorded the meeting using an audiotape and ensured that there was no distracting noise outside the venue during the meeting. I also invited a Xhosa speaking person who was a full-time volunteer at the church where I conducted the focus groups to help with translation where necessary and to check on the recording equipment. I used a discussion guide (see appendices 3, 4 & 5) that I had formulated from relevant questions that I needed answers to. I tried to direct the group to discuss the matters included in the discussion guide through giving a few “prompts” but without dominating the proceedings. The focus group took the form of a group discussion rather than a group interview where the emphasis is usually on questions and responses between the researcher and participants. When new topics emerged I allowed the discussion to continue unless I perceived it to be diverting from the issues that I needed to be covered.

3.2.3 Data analysis

Each focus group interview was recorded and transcribed verbatim to analyse the content. I also took note of non-verbal communication that accompanied what participants said with a view to determining if it conveyed any significant meaning. After transcribing the interview audiotapes, I analysed the data using the method proposed by Ary et al. (2006:490) which involves reducing and organizing the data, synthesizing it, searching for significant patterns and discovering what is important. A very similar procedure was described by Hancock (1998:17) who divided the process of *content analysis* (or the *manifest level of analysis*) into a series of ten steps. Lichtman (2010:197) describes the analytical process (consisting of six steps) in a similar way and explains the “three C’s of analysis – from Coding to Categorizing to Concepts.

Ary et al. (2006:490) suggest that analyzing qualitative data becomes manageable when broken down into three key strategies:

- i) familiarization and organization
- ii) coding and recoding
- iii) summarizing and interpreting

- Familiarization and Organization

This is the first stage of analysis which facilitates the easy retrieval of data. The researcher should initially become familiar with the data through reading and rereading notes and transcripts, listening repeatedly to audiotapes. Then the field notes, tapes, observations, comments and other data are put into a form ready for analysis, preferably typing it. Transcriptions should be made of all data, including tape-recorded interviews and focus groups. Words should be transcribed directly to avoid potential bias in selection or interpretation that may come with summarizing. Ary et al. (2006:490) suggest that as transcriptions are made, notes that provide non-verbal information (for example gestures, laughter) that can give added meaning should be included. Interestingly they warn against changing words or phrases that are grammatically incorrect as this could inadvertently change the sense or meaning of what was said. While doing the transcriptions identifiable information is removed and replaced with pseudonyms to ensure confidentiality. Once the transcriptions have been done, the researcher should continue to read and reread the data writing notes or memos in the margins (called reflective logs) to record his thoughts as they occur. An essential preliminary step to developing a coding scheme is to review the notes in the margins and make a complete list of the different types of information that are present. The major task of

organizing the mass of information starts after familiarization. The researcher should begin by creating a complete list of data sources. Ary et al. (2006:491) suggest that files may be organized in a variety of ways including by interviews, by questions, by people or by places and recommend that all data pages be photocopied and that the copies become the working documents. I organized my files according to interviews.

- Coding and recoding

This is the core of qualitative analysis and includes the identification of categories and themes and their refinement. Ary et al. (2006:492) equate coding to preparing for a garage sale. The goods for sale are sorted into categories like housewares, clothing, furniture, books et cetera. The categories are then further subdivided e.g. clothing may be subdivided into children's, teenagers' and adults' clothing. Children's clothing, for example, may be further subdivided into infants, toddlers and school age clothing and then even further subdivided into boys' and girls' clothing.

The first step in coding, according to Art et al. (2006:492), is referred to as open coding, preliminary coding or provisional coding. The most widely used approach is to read and reread all the data and arrange them by looking for units of meaning like words, phrases, sentences, subjects' ways of thinking, behaviour patterns and events that seem to appear regularly and that seem important. The label given to each unit of meaning should be understandable even without any extra information. The authors suggest that as many codes as necessary should be used at first because the coding is helpful in recognizing differences and similarities in the data. The initial coding leads to the development of tentative categories.

After all the data are coded, the researcher now places all units having the same coding together – either manually (cutting with scissors according to the codes and putting material with the same codes together in a marked folder) or using highlighters with a master sheet indicating which colours are connected with which categories.

Once the coding of a transcript is completed and all items with a particular code are placed together, the researcher reviews the sets of items to make sure they belong together. The next step then is to start deciding whether codes can be grouped together into larger categories. Once categories have been decided upon, the researcher considers whether some categories may be linked to create major categories or themes. This process of coding, categorizing and developing themes will be repeated for each transcript or set of data.

At this point these sets are merged together and the researcher reviews the categories and themes. It may be useful to revisit the original transcripts to see if any areas are not coded and to consider whether these now fit into categories that the researcher has developed. The authors caution that the categories developed from the coded data should be internally consistent and distinct from one another.

Bogdan and Biklen (1998) are quoted in Ary et al. (2006:493) offering a number of categories that might be used: setting/context, definition of the situation, perspectives held by subjects, subjects' ways of thinking about people and objects, process, activity, event, strategy, relationship and social structure and methods.

If the number of categories is very large, Ary et al. (2006:494) suggest that they be collapsed into a manageable number. Once the data pieces have been coded, they are merged into categories that are refined through several iterations and the researcher explores the patterns across categories and through this process identifies major themes.

- Summarizing

Now that all data have been sorted into major and minor categories, the researcher considers whether some of the categories fit together into themes. The next step is to summarize - which is the stage at which one begins to see what is in the data. The researcher examines all entries with the same code and then merges these categories into patterns by finding links and connections among categories. This process makes it possible for the researcher to make some statements about relationships and themes in the data. Summarizing, therefore, is when the researcher starts to make meaning of the categories and themes and to connect them.

There are two commonly used ways of analysing qualitative data viz. *constant comparison* and *negative case analysis*.

The *constant comparison method* according to Glaser and Strauss (1967) as quoted in Ary et al. (2006:499) entails combining inductive category coding with simultaneous comparison of all the units of meaning that have already been obtained. The researcher studies each new unit of meaning (topics/concepts) to find its unique characteristics. Then he compares categories and groups them with similar categories and if there are no similar units of meaning he forms a new category. There is therefore a process of ongoing refinement. This is the process I chose to follow.

In using the *negative case analysis method*, the researcher looks for data that contradict the main category or pattern. A method known as *discrepant data analysis* entails looking for data that provide a different perspective on a category or pattern. According to Ary et al. (2006:499) this approach gives a counterbalance to a researcher's tendency to stick to hunches or first impressions.

I also came across two other methods for mapping of themes described by Thomas (2009: 198 – 200) which he referred to as *network analysis* (where the researcher aims to show how one idea is related to another using a network) and *construct or theme mapping* (where themes are put in sequential order from the interview and lines and arrows are used to make connections between the ideas and themes).

- Interpreting

Hancock (1998:170) points out that interpreting, which she refers to as the *latent level of analysis*, is a higher level of analysis and is concerned with what was meant, inferred or implied by the response.

In interpreting qualitative data, Ary et al. (2006:500) explain that you:

- confirm that what you already know is supported by the data;
- question what you think you know and get rid of misconceptions;
- take note of new insights and important things that you did not know but should have known.

Interpretation also includes evaluating the plausibility of some of the hypotheses that may have developed during the analysis. Hypotheses are tested by going through the data again and searching for supporting data as well as negative or deviant cases.

Despite interpretation being a subjective process and generally happens outside of a set rules, Ary et al. (2006:500) warn that it should be backed up by data.

Through content analysis of the data the following five themes emerged from the focus groups as well as the case studies: the precipitating factors leading to guardianship of grandchildren by grandparents; the stressors and challenges faced by grandparent-caregivers and orphaned grandchildren; the ongoing needs of grandparents and orphaned grandchildren; the resilience of grandparents and orphaned grandchildren; and external support available to grandparent-headed

households. Despite the fact that I analysed the data according to these five recurring themes I chose to discuss the data on a case by case basis to capture in-depth information about every family, individual and organization.

3.2.4 Selection of respondents for the focus groups

3.2.4.1 Grandmothers caring for orphaned grandchildren group

I made use of *purposive* sampling to select respondents for this particular focus group. Neuman (2006:222) explains that purposive sampling is a non-random sample in which the researcher utilises a variety of methods to find all possible cases of a highly specific and difficult-to-reach population. For this group I relied on the assistance of a pastor of a church to identify and recruit gogos to participate in this study and they in turn suggested other gogos that could be approached.

3.2.4.2 Stakeholders group

A stakeholder, according to Buchholtz and Carroll (2008:84) is an individual or a group that has one or more of the various kinds of stakes (viz. an interest, right or ownership) in an organization. Just as stakeholders may be affected by the actions, decisions, policies, or practices of the organization, stakeholders also may influence the organization's actions, decisions, policies or practices. The key stakeholders in a business organization, for instance, would be creditors, customers, directors, employees, shareholders and the community from which the business accesses its resources. Since I knew of only two established organisations in Port Elizabeth offering support to grandparent-headed households, I again made use of *purposive* sampling (which, in McMillan and Schumacher [2001:175] is also referred to as purposeful or judgemental sampling) to select respondents for this focus group. I also invited a pastor of a church in Motherwell Township who was in the process of launching an outreach programme for grandmothers and orphans and vulnerable children. Since one of the grandmothers, who had attended the focus group for grandmothers, had set up a support group on her own initiative I also invited her to this focus group.

3.2.4.3 Orphans from grandparent-headed households group

I made use of *purposive* sampling in selecting this group. At the end of the first focus group, I asked which of the grandmothers in attendance were caring for grandchildren between the ages of fourteen and

nineteen years, and of those to agree to ask those grandchildren if they were willing to participate in a focus group with their peers.

3.3 CASE STUDIES

Cohen and Manion (1998:106) describe the case study researcher as one who observes the characteristics of an *individual unit* like a child or class or a community as opposed to a surveyor who asks standardized questions of large, representative samples of individuals. According to McMillan and Schumacher (2001:36) a case may be a programme, an event, an activity, or a set of individuals who are situated in the same place and time. Neuman (2006:40) explains that because the researcher intensively investigates one or two cases, the data from case studies are usually more detailed, varied and extensive. The researcher considers the context of a particular case and tries to determine how its parts are configured. Cohen and Manion (1998:107) suggest that the case study is widely used in modern social science and educational research and various techniques are used to collect and analyse both qualitative and quantitative data but whatever approach is used, these authors believe that a method of *observation* lies at the heart of every case study. Toseland and Rivas (2005:405) assert that the strengths of case studies are that they can provide a clear and detailed description of the processes and procedures of a group in action and are often more practicable to use in practice settings than in control-group designs.

3.3.1 How to undertake case study research

According to O'Leary (2004:117) one of the most important aspects to keep in mind when conducting a case study is selecting the right case - by which O'Leary meant that it should provide the researcher with sufficient data to make relevant arguments. The criteria I used for defining my family case studies was that each family would be headed by grandparents or a single grandparent older than sixty years who are/is caring for orphans between the ages of fourteen and nineteen years. I selected my cases using a non-random sampling method simply by handpicking them on a pragmatic basis ensuring that both cases met the criteria I had set. My fieldwork which involved interviewing (using semi-structured questions) was now carried out. I had the opportunity of going to Cape Town on a work-related assignment and used this opportunity to visit a programme called G.A.P.A. which supports grandparents in the Khayelitsha Township. I used this organisation as a third case study.

Noor (2008:1604) is of the opinion that two or more cases should be included within the same study because the investigator predicts that similar results (replication) will be found. Noor also believed that by

examining a number of cases, the accuracy, validity and reliability of the results is enhanced and the researcher is able to draw conclusions from consistent findings.

3.3.2 Types of case study

Robson (2002:181) refers to the following types of case study and explains the range of purposes they fulfil:

Individual case study: This is a detailed account of one person. It usually focuses on the person's past history, contextual factors, perceptions and attitudes that precede a known outcome (e.g. drug use; immigrant status). It is used to explore possible causes, determining factors, processes, etc., contributing to the outcome.

Set of individual case studies: This is the same as the individual case study except that a small number of individuals with some features in common are studied.

Community study: This is a study of one or more local communities. The study describes and analyses the pattern of, and relations between, main aspects of community life like politics, work, leisure, family life etc. It is usually descriptive but may explore specific issues or be used in theory testing.

Social group study: Both small direct contact groups like families and larger more widely-spread ones like occupational groups are covered by this type of study. It describes and analyses relationships and activities.

Studies of organisations and institutions: These are studies of firms, workplaces, schools, trade unions, etc. The studies focus on a variety of issues like best practice, policy implementation and evaluation, industrial relations, management and organisational cultures, change processes and adaptation etc.

Studies of events, roles and relationships: These studies focus on a specific event. They are very diverse and may include studies of police-citizen interactions, doctor-patient relationships, specific crimes or significant happenings like disasters, studies of role conflicts, stereotypes, etc.

3.3.3 Choice of a case study method for the present study

I chose the *social group case study method* for the two grandparent-headed families because my focus was on their experiences, problems, coping methods and needs. I also concentrated on the relationships

between the grandparents and their grandchildren in these reconstituted families. The G.A.P.A. case study was in fact a *study of an organisation and institution* as my goal was to discover how they functioned so that I describe their systems in providing for the needs of grandmothers caring for their orphaned grandchildren.

3.3.4 Selection of respondents for the two family case studies

Two families consisting of orphaned children between the ages of fourteen and nineteen years and grandparents who were sixty years of age or older who were heading up the reconstituted households were selected for the case studies. The first family was selected by means of *purposive* sampling. After my interview with the management team of G.A.P.A., I asked them to identify a grandparent-headed family consisting of orphaned children between the ages of fourteen and nineteen who were available and willing to be interviewed during the week that I was in Cape Town. On a separate work-related trip to Johannesburg I selected a second family case study through an organisation called Cotlands which supports grandparent-headed households in Soweto.

3.3.5 Selection of the data gathering method for the case studies

For the purposes of this research, interviews were chosen as the data gathering method.

3.3.5.1 Interviews

Neuman (2006:305) defines the interview as a short-term, secondary social interaction between two strangers with the specific goal of one person getting particular information from another person. Research interviewing, however, is a specialised kind of interviewing and differs in a number of ways from ordinary conversation. For example, in the research interview only the respondent reveals feelings and opinions while in an ordinary conversation there is an open exchange of feelings and opinions. The interviewer in the research interview is non-judgemental and does not try to change the respondent's opinions or beliefs as opposed to a normal conversation where judgements are stated and both people involved in the dialogue try to persuade each other of particular points of view. Cannell and Kahn (1968) are quoted in Cohen and Manion (1994:271) defining the research interview as "a two-person conversation initiated by the interviewer for the specific purpose of obtaining research-relevant information, and focused by him on content specified by research objectives of systematic description, prediction, or explanation".

Cohen and Manion (1994:272) suggest three purposes of the interview as a particular research technique. *Firstly* it may be used as the main tool for gathering information which has direct bearing on the research objectives. In this regard Tuckman (1972) is quoted in Cohen and Manion (1994:272) suggesting that the interview gives one access to what is “inside a person’s head” and makes it possible to measure what an interviewee knows, what they like or dislike and what they think. *Secondly* the interview may be used to test hypotheses or to suggest new ones or as an explanatory mechanism to help identify variables and relationships. *Thirdly*, the interview may be used to follow up on unexpected results or to explore the rationale of respondents’ responses.

Qualitative interviews, according to McMillan and Schumacher (2001:443), may take a number of forms: the *informal conversational interview*, the *interview guide approach* and the *standardized open-ended interview*. These types of interviews differ in their degree of structure and planning and the measure to which responses can be compared in data analysis.

In the *informal conversation interview* the immediate context determines the questions that are asked; the topics are not predetermined and questions are asked in the natural flow of the conversation. This type of interview is typically used during participant observation.

In the *interview guide approach* (also known as the semi-structured interview or the non-scheduled standardised interview [Goetz and LeCompte, 1984:119] and the approach I adopted) topics are predetermined but the researcher decides on the order and wording of questions during the interview. The two types of interviews mentioned to date are somewhat conversational and situational.

In the *standardised open-ended interview*, participants are asked the same questions in the same order which obviously reduces the flexibility which the interviewer enjoys in the previously mentioned types of interviews. Questions are completely open-ended in this type of interview.

Powney and Watts (1987:24) argue that no one approach is inherently better than another. They have all been developed and used with certain needs in mind.

3.3.5.2 Motivation for the use of a semi structured interview

Since I was hoping to gain an in-depth understanding of the grandparent-headed families, their functioning, challenges, needs and life-worlds in general I decided that the medium that would yield the richest data would be the semi-structured interview. I learned, from my literature study, that the likelihood

of this set of grandparents having a lower level of education would be fairly strong and for that reason I decided against using a medium like a questionnaire which would call for a higher level of literacy. Rosnow and Rosenthal (1996:112) outline the following advantages to the face-to-face interview: (1) It gives an opportunity to connect with the subjects and to build trust and cooperation which are necessary when probing sensitive areas; (2) It allows for helping the subjects in their interpretation of the questions; and (3) It offers a measure of flexibility in deciding on the wording and sequence of the questions by giving the researcher more control over the situation (e.g. by allowing the interviewer to decide there and then the amount of probing that is required).

My rationale for using the semi-structured form of interview was that I wanted to ensure that I asked the same questions and used the same probes with both families but wanted the freedom to respond in the moment to any dynamics during the interview. I also felt that it suited my usual communication style which is natural and responsive and that I would be perceived as being genuine if I followed this form of interviewing. I realised, too, that it was highly likely that I would acquire information that I had not planned to ask for and in fact hoped that this would occur.

3.3.5.3 Data collection

The following table outlines the six steps involved in conducting case study research and explains how I carried out each step of the process:

PROCEDURE FOLLOWED IN CASE STUDY RESEARCH

Step	Description
1. Determine and define the research question	<p>I used the following sub-problems as my guide to determining what I needed to find out empirically:</p> <ul style="list-style-type: none"> • What are the needs of orphaned children? • What are the characteristics of grandparent-headed households? • What helping services are presently in place for grandparent-headed households? • What are the views and experiences of two grandparent-headed households? • What are the views of stakeholders with regard to the phenomenon of grandparent-headed households?

	<ul style="list-style-type: none"> • What are the guidelines for professionals and lay people who endeavour to empower grandparents fulfilling the role as parents in the context of the HIV/AIDS pandemic?
2. Select the cases and determine data gathering technique	<ul style="list-style-type: none"> • I chose three cases: 2 grandparent-headed families in Meadowlands (Soweto) and Khayelitsha respectively and a Non-Government Organisation (G.A.P.A) serving grandmothers in Khayelitsha (Cape Peninsula) believing they would provide sufficient data. I used the following criteria for selecting my cases: <ul style="list-style-type: none"> - Each family to be headed by grandparents older than 60 years - Grandparents who are guardians to orphans between ages of 14 -19 years - The organisation focuses on the needs of grandparent-headed households • I used the semi-structured interview as my data gathering technique
3. Prepare to collect data	<ul style="list-style-type: none"> • I formulated appropriate questions for the interviews with families and stakeholders. • I finalised dates and times of interviews with the help of NGO's • Ensured that consent forms were sent out and signed by interviewees. • Established rules for confidentiality.
4. Collect data in the field	<ul style="list-style-type: none"> • Collected the consent forms. • Visited the homes of two identified families in Soweto and Khayelitsha respectively and conducted interviews. • Recorded each session with audio tape and made notes. • Visited GAPA in Khayalitsha and conducted an interview with the director.

	<ul style="list-style-type: none"> Recorded the interview and made notes.
5. Evaluate and analyse data	<ul style="list-style-type: none"> Used the method suggested by Art et al. (2006:490) to analyse the data namely familiarization and organization; coding and recoding and summarizing and interpreting.
6. Prepare the report	<ul style="list-style-type: none"> This dissertation is the report.

I obtained permission from both families as well as the G.A.P.A. management team to tape record the respective interviews and to transcribe them and assured them of confidentiality in the research report for ethical reasons. I used a small unobtrusive tape recorder and kept note-taking to a minimum to facilitate the free flow of information and communication. My introduction to both families as well as to the G.A.P.A. personnel, which included a brief explanation of the purpose of the study and minimal information about me, was similar.

I recorded the issues that I had anticipated the respondents focusing on during the interview (having encountered them during my literature investigation), on a grid before each session. I then marked the issues as they were covered during the interview. Issues that emerged which, in my view, needed further clarification and new trends and dynamics that I observed during the interview were also marked down. I then ensured that the issues were clarified either immediately or before the end of the session.

3.3.5.4 Data analysis

- Familiarization and Organization

I became familiar with the data by reading and rereading notes and transcripts and listened to the audiotapes a number of times. My notes and transcripts were typed to enable me to analyze them. I continued reading the data and made notes (reflective logs) in the margins to record my thoughts as they occurred. I then reviewed the notes I had made and compiled a list of the different types of information that were present.

- Coding and recoding

My first step was to read and reread all the data and arranging them by searching for units of meaning like words, phrases, sentences, subjects' ways of thinking, behaviour patterns and events that appeared regularly and stood out. After coding all the data I placed all units having the same or similar coding together by using highlighters with a master sheet which indicated what category each colour represented. I made sure, once all the items with the same code had been grouped, that the sets of items in fact belonged together. I then looked for codes that could be grouped together into bigger categories and continued this process considering whether some categories could be linked to form major categories or themes. I basically followed this process for each transcript.

It was at this stage that I merged these sets together and reviewed the categories and themes. Once the data pieces had been coded, I combined them into categories that were refined even further and I considered the patterns that had formed across categories and through this process I identified major themes.

- Summarizing

This was the stage where I started to make meaning of the categories and themes and to connect them.

- Interpreting

Here was where I thought about what was meant, inferred or implied by the various responses. I analysed the data according to the same five recurring themes which emerged from the focus groups.

3.4 CONCLUSION

Chapter three provided a detailed description of the research methodology used in my empirical investigation of grandparent-headed households. The main research problem as well as the sub-problems that were explored was stated. The qualitative research methods of *focus groups* and *case studies* were explained in detail in terms of their theoretical background; motivation for their use in the present study and the collection and analysis of data.

In chapter four the data analysis as well as the discussion and interpretation of the results of my empirical research are discussed. The criteria for establishing guidelines will be selected from the data and will also be discussed in the next chapter.

CHAPTER 4: INTERPRETATION OF RESEARCH FINDINGS

4.1 INTRODUCTION

Chapter three provided a detailed description of the research methodology used in my empirical investigation of grandparent-headed households. Chapter four presents the analysis and interpretation of the empirical research.

4.2 FOCUS GROUPS

4.2.1 Grandmothers caring for orphaned grandchildren group

The focus group consisted of six grandmothers from the township of Motherwell in Port Elizabeth and took place at the church office in Motherwell. All the grandmothers were isiXhosa speaking and since only one of the grandmothers was conversant in English I made use of a translator – a fulltime church volunteer.

4.2.1.1 Biographical profile of grandmothers

Four of the grandmothers were between the ages of sixty and sixty five years and two were older than seventy years. One of the grandmothers still had her life-partner living with her while all the others were single. Two of the grandmothers were each caring for only one adolescent orphan, three grandmothers were each caring for two orphaned adolescents (who were each other's cousins) and one grandmother was caring for her grandson as well as her late brother's two adolescent children i.e. her niece and nephew. Two focus group members were maternal grandmothers while three were paternal grandmothers and one was not a biological grandmother but caring for her late-brother's son and grandchild. Two of the grandmothers had never received any formal education while three had six years of schooling or less. One of the grandmothers had successfully completed standard eight (grade ten). The respondents' names have been replaced by pseudonyms to ensure their confidentiality.

During the data analysis the following categories emerged: precipitating factors leading to guardianship of grandchildren; grandparents' stressors; sex, HIV and AIDS; needs of grandparents; orphans' needs; spirituality of grandparents.

4.2.1.2 Precipitating factors to grandmothers becoming guardians to their grandchildren

Mama Anthea has been caring for her grandson for the past eighteen years after he was abandoned by his mother, Mama Anthea's daughter, who has not made contact in all those years.

Mama Busi had no option but to become the caregiver to her grandson after both his parents died in close succession from AIDS-related illnesses.

Mama Catherine's son and father to her grandchild is HIV positive. The grandchild's mother, whom Mama Catherine has not met, sent the child with her friend and simply dropped him off at Mama Catherine's house a number of years ago. Mama Catherine has also been the caregiver to her adolescent niece and nephew after her brother died from an AIDS-related illness.

Mama Dora, whose brother also died from an AIDS-related illness, took over the responsibility of raising his son and now also raises her late-brother's grandchild, whose mother is HIV positive and lives in another town in the Eastern Cape.

Mama Eve began raising her grandson after her son died from an AIDS-related illness and the mother, who lives in another Eastern Cape town, abandoned the child with her.

Mama Florence, who is still married, became the guardian of her two adolescent granddaughters after their mothers, Mama Florence's daughters, died within months of each other, from AIDS-related illnesses.

4.2.1.3 Self-reported health status

All six participants reported that they were receiving treatment for hypertension. One of the grandmothers was diabetic and two mentioned that they experienced a lot of pain in their legs due to arthritis. All of them visited the local health clinic on a monthly basis.

4.2.1.4 Self-reported emotional status

Five of the six grandmothers reported that they were stressed. Two participants attributed their stress to the criminal activities that their grandchildren were involved in. One of these mentioned that she had been so stressed the previous week that she had collapsed. Three participants attributed their stress to financial constraints. One grandmother mentioned that apart from being concerned about her grandson's future she was "okay". Everyone in the group conceded that they were worried about things and four of

the group members mentioned that they sometimes felt sad and depressed. They all reported having trouble sleeping.

4.2.1.5 Sources of income

Every grandmother in the group received a state pension of R1080 per month and two caregivers each received a child support grant of R250 per month. Mama Florence's husband also received a pension of R1080. One participant stated that she supplemented her income by selling sweets, polony and juice to her neighbours.

4.2.1.6 Actual living expenses

Every focus group member complained that their pensions were hopelessly inadequate and all believed that an additional R1000 per month would help them to make ends meet given that their grandchildren needed clothing, stationery, taxi fare, et cetera.

4.2.1.7 Financial coping strategy

The grandmothers in the group all mentioned that their pensions provided for their most basic needs for approximately two weeks in every month. When asked how they coped for the remainder of the month, they sheepishly answered that they made use of loan sharks whom they referred to as *Skoppers*. I was informed that *Skoppers* lent money at an interest rate of 50%. So for every R100 they borrowed from the *Skopper* they had to repay R150 and most of them borrowed an average of R300 per month. On pension day they collected their identity documents from the *Skopper* who loitered in the vicinity of the payout point and as soon as they had received their pension the grandmothers paid the *Skopper* R450 which was owed to her. I learned that *Skoppers* were mainly women living in the township generating income by lending money at exorbitant interest rates to desperate pensioners. As mentioned, one grandmother supplemented her income through selling sweets, polony and juice but she, too, made use of *Skoppers*. Without the additional income they mentioned that they would have to go without electricity and sugar for the remainder of the month. The group acknowledged that they were caught up in a cycle of debt and were getting steadily poorer.

4.2.1.8 Supporting grandchildren with school work

When asked about how they managed to support their grandchildren with their homework given that many of them had not had the opportunity to advance very far in their own education, two participants

mentioned that their grandchildren tried to do their homework on their own and the other four stated that they sought the help of older youth whom they knew from church or were neighbours' children. They all acknowledged that they were not able to be of much assistance to their grandchildren in this regard but tried their best "to make a plan" by asking senior scholars in the neighbourhood to help their grandchildren with their schoolwork. The actual schools that their grandchildren attended did not offer any additional scholastic support to learners. One grandmother also mentioned that her granddaughters regularly visited the local municipal library where they did their homework and did research for school projects.

4.2.1.9 Grandmothers' major difficulties

I asked the focus group members about what was most difficult at their age about raising grandchildren. Four grandmothers stated that their poor state of health ("My health is going down.") was their major concern and linked to this was their fear that they would not be able to have sufficient strength or be able to live long enough to ensure that their grandchildren's futures were reasonably secure. Two grandmothers expressed their concern about their grandchildren's behaviour and stated that their inability to manage their behaviour was a major stressor. One grandmother mentioned that not having enough money to meet all her grandchild's basic needs was very difficult for her.

4.2.1.10 Speaking to grandchildren about sex and HIV/AIDS

Five of the six grandmothers mentioned that they had spoken to their grandchildren about sex and HIV/AIDS but as one grandmother said, "Not too much" meaning that they had not gone into any detail with regard to this topic. They had broached the subject in different ways: one grandmother said that whenever she visited the clinic, she usually took a handful of condoms and placed them under her grandson's pillow when she got home and to date she had never heard him enquire about the condoms so she assumed he was using them; another grandmother mentioned an isiXhosa term which evidently equated to "His ears are getting big" meaning that her grandson was at an age where he was ready for sex so she simply told him to go to the clinic to fetch condoms for himself and to make sure that he did not get the virus; another grandmother spoke of having a conversation with her grandson where she told him about the consequences of unprotected sex and pointed out that there was nothing she could do about those consequences; one grandmother said that she reminded her grandson about how sick his father was and how she had to care for him and hoped that this conversation had made some impact on him; one grandmother had used the opportunity, when a teenage pregnant girl walked by her home, to point out to her granddaughters that this should not happen to them and that if they developed a

friendship with a boy that he should be tested for HIV and that they should always make sure that the boyfriend was using a condom before they engaged in sex. The group then discussed the fact that many young people in the township did not know their HIV status and the unknown was “getting to them now” and was making them rebellious and young people were using drugs and alcohol “just to forget”.

4.2.1.11 Support received to date

No one in the group was aware of any organisation offering psycho-social support to grandparents caring for their orphaned grandchildren. Two of the participants, however, named Mama Florence as one person from whom they received regular, on-going support. Mama Florence, on her own initiative, had started a support group for grandmothers in her neighbourhood caring for their orphaned grandchildren. Every Tuesday afternoon, a group of grandmothers met at Mama Florence’s home and enjoyed a cup of tea or coffee (provided by Mama Florence) and shared their difficulties with each other and prayed for each other. This time was also used to teach the grandmothers skills like beading, sewing, knitting and crocheting to encourage them to produce goods that could be sold for additional income. They mentioned that these sessions gave them “peace of mind”. Mama Florence shared that she had started this group because she was not receiving any support and realised that there were others in her street that were in a similar situation. The group was very complimentary toward her because of her giving spirit and the grandmothers in Mama Florence’s group spoke of how much they benefited from this weekly gathering. Mama Anthea shared that her daughter-in-law sometimes visited her to “see how I’m doing” and usually brought some food for her when she visited. She mentioned also that she had received no support from her church. Mama Eve mentioned that her pastor’s wife sometimes gave her some emotional support while Mama Catherine spoke of getting spiritual support from the other grandmothers in her church. Mama Dora said that she sometimes shared her difficulties with her neighbours and usually felt a little better afterwards.

4.2.1.12 Suggestions to organisations wanting to support grandparent-headed households

The grandmothers were asked to think about suggestions they could offer an organisation whose mission it was to be effective in meeting the needs of grandparent-headed households. I tried to get them to consider needs other than the obvious physical needs that they had already expressed during this focus group session. It was evident that the physical needs were so pressing that the participants struggled to consider other less tangible needs. The need for food was the first need that any such organisation would need to address, according to most participants. Grandparents needed assistance in acquiring school uniforms, stationery and sports equipment for their grandchildren and also to have someone advocate on

their behalf to be exempted from paying school fees for their grandchildren. Grandmothers needed these organisations to provide tutors to help their grandchildren with their homework. They expressed the need to have someone helping them navigate the bureaucratic systems in place to acquire RDP housing. The discussion eventually progressed to other needs such as helping grandmothers to manage the behaviour of their grandchildren and it was felt that the said organisation should speak to the grandchildren themselves about their inappropriate behaviour. Grandchildren in these circumstances needed mentors to guide and motivate them. The group also discussed the grandchildren's need for counselling to address issues such as the stigmatisation and victimisation they were subjected to by their peers because of their HIV + status; to receive emotional support with regard to their grief at losing their parents and to help them understand the finality of death and that "Gogo is not holding them hostage," as one participant mentioned. It was also mentioned that grandparents needed an organisation which could set up support groups for them where they could come together, share their problems and "feel free to speak out, like at Mama Florence's house."

4.2.1.13 Source of grandmothers' resilience

When asked what kept them going despite the hardships they had described during this session participants unanimously agreed that their faith in God was what sustained them. One participant mentioned that she prayed many times a day and that she even woke up early every morning to pray.

4.2.1.14 Synthesis and conclusion of focus group

My respect for this seldom-acknowledged life-force of the community increased tremendously as a result of this focus group. I learned that grandmothers' nurturing role comes very naturally to them and they are willing to make huge sacrifices at tremendous cost to their own health and emotional well being. The fact that most grandmothers in townships around South Africa live in sub-standard living conditions exacerbates the difficulties of their task. I was impressed that grandmothers were in this substitute parenting role for the long haul. They are very aware of their mortality and are very concerned about the permanency planning for their orphaned grandchildren. A huge area of need is for agencies to recognise their loss and grief as a result of losing their own children to HIV/AIDS and to respond with psychosocial support. Their lack of financial savvy is a concern and would also need to be addressed. The fact that the subject of sex is regarded as taboo must surely be fertile breeding ground for the HI virus to continue spreading. Grandmothers struggle to manage their grandchildren's behaviour which is a source of stress to them. Their faith in God is obviously a factor that builds resilience in grandmothers.

4.2.2 Stakeholders group

The stakeholders group consisted of co-ordinators of two established non-government organisations offering support to grandparent-headed households in Port Elizabeth (GoGo Trust and LoveLife – goGogetters programme) as well as the pastor of a church in Motherwell who was in the process of launching an outreach programme for grandmothers and orphans and vulnerable children. I also invited Mama Florence to attend this focus group. There were four participants in total in this focus group.

4.2.2.1 Involvement with grandparent-headed households

I asked the co-ordinators to explain how their respective organisations were presently involved with grandparent-headed households.

Sharron Froot began by explaining that the GoGo Trust was a non-profit organisation with two strands of DNA – firstly to care for widows and the other to care for orphans. As a member of the Kwazakhele Health and Welfare Forum she had been introduced to five grandmother-headed families which were taking care of AIDS orphans. The forum requested Sharron to set up a support group for these and other grandmothers who had the responsibility of caring for AIDS orphans in their families. The initial group, which was established in April 2002, consisted of twenty grandmothers whose adult children had died of AIDS and they were each caring for between two and ten AIDS orphans in their own families. The GoGo Trust focused on meeting the spiritual and emotional needs of grandmothers caring for their orphaned grandchildren by facilitating weekly support group meetings for them. Every Tuesday widows, who were leaders in their communities and local churches, met for “fellowship, encouragement and teaching”. The aim of this meeting was to strengthen and support these leaders to assist them in supporting and caring for AIDS orphans within their families and surrounding communities. At this meeting the leaders were trained in financial management, leadership and discipleship in the Christian faith. They were served a nutritious meal during these meetings and given bread to take home for their grandchildren. Each of these ladies was a leader of a *soup cell* which they ran in their own homes throughout the week. Each *soup cell* leader was given a 25kg bag of soup. There were presently ten *soup cells* reaching more than three hundred people a week in Kwazakhele and surrounding communities. The aim of these *soup cells* was to draw the community members together for support. The soup made in these *cells* was given to orphans in the community and to community members receiving drug therapy for TB and for HIV/AIDS. One positive effect of the *soup cell* was that it gave the leader a sense of purpose and well-being so that she did not feel so overburdened by the situation in her community and that she was actually in a position to meet the needs of many. Sharron explained that two of the *soup cells* ran sewing projects to generate

income for the gogos working in them. They made items such as bedding, towels, school clothing and traditional clothing. The GoGo Trust provided the equipment for these sewing projects. Other *soup cells* ran beadwork projects which sold products to local and overseas markets. Seventy five percent of all beadwork sold went to the person who had made the beadwork item and the remaining twenty five percent to the GoGo Trust to replenish stock.

A project linked to the GoGo Trust called *Sisonke Sophumulela* (in isiXhosa means *Together we can overcome*) was established to focus on the needs of the orphans in grandparent-headed homes. The programme which was staffed by a manager and four child care workers was administrated from an office facility in Kwazakhele Township. The programme offered a number of services to orphans living in grandparent-headed homes. Firstly the child and youth care workers conducted home visits to all sixty nine families in the programme. There were weekly support groups for these young people. An interesting concept that Sharron described was *accompanied food shopping* where the child and youth care workers went with the orphans to a local retail store to guide them in purchasing basic food items for their homes with money provided by the GoGo Trust. The project also provided fuel for cooking and home lighting. The youth in the project were given support through prayer and counselling. Through the project manager and the child care workers children were able to be referred to other support services such as psychologists, dieticians and grief counselling. The programme included activities such as camping, road running, dance, poetry, play writing and outings. An important component of the *Sisonke Sophumulela* project was educational support where young people's school fees were paid, uniforms provided, study skills were taught and after school study programmes were offered. Learners in grades ten to twelve were offered an employment training course during the June holidays where they were trained in writing a curriculum vitae, finding employment opportunities and in how to conduct themselves in an interview situation.

Lulu Zwane, whose contract with loveLife as the provincial Co-ordinator of the goGogetter programme had recently ended, described that they had recruited one hundred gogos in the Eastern Cape and trained them in how to support orphaned and vulnerable children. The programme identified grandmothers as key people in championing the cause of vulnerable young people in the community because as Lulu said, "They know how to keep their own children at home and have passion for children." Lulu explained that part of her job was to teach the gogos to reach out to vulnerable young people in the community who were directionless and lacked adult guidance and giving them a sense of belonging and purpose. They had found that when a young person was connected to a gogo he tended to change his attitude and began to confide in the gogo. Gogos were also trained to identify the needs

and challenges of these young people by visiting them in their own homes and linking them with resources in their communities, both private and government agencies. If, for example, a goGogetter worker came across a home where a grandparent was caring for a number of orphaned children for whom she was not receiving a welfare grant, the worker would assist the grandparent in accessing the applicable grant (either the foster care grant or the child support grant). Gogos also visited schools, clinics and churches in order to reach more children and youth at risk. Gogos were mandated to report any incidents of child abuse that they had come across while doing their home-visits. A major focus for goGogetters was keeping children in school. Lulu explained that the workers were encouraged to make use of matriculants in the community who had not yet found employment to mentor the vulnerable children who were struggling at school. Lastly the goGogetters were encouraged to organise monthly events in their respective communities where invited guests would speak on issues pertinent to that community.

Pastor Sam Banzi from the African Gospel Church in Motherwell explained that his church was very community oriented and that he had a real passion for young people. He and his church leadership team had very recently made the decision to establish a programme called *Kingdom Women in Leadership* which would concentrate on the needs of gogos and orphaned and vulnerable children in Motherwell Township. He mentioned that since Lulu was no longer working for loveLife that they had approached her to become involved in their programme so that the skills she had gained while co-ordinating the goGogetter programme could be 'imported' to their *Kingdom Women in Leadership* programme. Lulu had helped them to understand the potentially valuable role that gogos in the community could play in meeting the needs of orphaned and vulnerable children once they had been empowered through training and support. He emphasised that the programme had not yet been launched but that they were busy putting structures in place to begin the project early in 2011. Their plan was to allocate between five and ten children to each gogo in the programme to offer similar services to those offered by the goGogetter grannies. The gogos would be trained in identifying resources in the community to which they could direct other gogos and learning how the system for applying for grants and pensions worked. They would make a concerted effort in acquiring birth certificates for orphans in the programme so that their grandparents were able to access the relevant grants. Pastor Banzi mentioned that he was very concerned about the present situation where gogos were being exploited financially by younger relatives who took possession of their bank cards and used up all the grant and pension money on themselves. "They must have control over their own money," he said. When asked how they would train the gogos, he explained that they were planning an open day to which all the gogos in the church and in the immediate community would be invited. At this event, the views of the gogos regarding their needs, limitations and the skills they

possessed which could be of benefit to other grandparents in the community would be sought. An informal skills audit would be done and the gogos would then be categorised into different “levels”. Pastor Banzi mentioned that once this had been done they would then allocate tasks to the various teams of gogos who by then would have been grouped according to their category of skill. Workshops for each team would then be held where the gogos would be empowered and their skills enhanced even further. They would then be released to serve the needs of gogos and orphaned and vulnerable children in the community. Weekly leadership meetings would be held where their own needs, concerns and successes would be shared with other gogo leaders. One of Pastor Banzi’s goals was to employ a nurse and acquire the services of a medical practitioner who would regularly visit the gogos in their homes and administer their medication and respond to their medical needs to avoid them having to wait in long queues at public clinics.

Mama Florence was rather reluctant to share what she was doing because she felt that her work was insignificant compared to the programmes that the previous speakers has described. The group, however, encouraged her to share explaining that everyone was doing significant work notwithstanding the size of the project. She then explained that she had created a support group for grandmothers in her street who were caring for their orphaned grandchildren because she herself had felt overwhelmed, stressed and often depressed and did not have any “outside support” and assumed the other grandparents felt the same way. Each Tuesday morning the gogos met in Mama Florence’s home and discussed their problems and they shared their sewing and beadwork skills with each other. On Tuesday afternoons, the orphaned grandchildren came to Mama Florence’s home where she and a friend played games with them, read scriptures to them and spoke to them about how they should behave at school. They taught different life skills each week. She also gave the children bread and fruit juice which she paid for herself. The other focus group members congratulated Mama Florence on the work she was doing and encouraged her to continue and to network with them.

4.2.2.2 Profile of grandparents caring for their orphaned grandchildren

The typical characteristics of a grandparent seeking help from the GoGo Trust was that she would be a Christian grandmother involved in a local church or community initiative. Her own children would have died of AIDS and she would be left with the sole burden of raising and caring for between two and ten orphaned grandchildren. She would be between forty eight and seventy years of age and would be a widow. Sharron mentioned that most grandparents in her programme had grown up in the Transkei or

Lesotho and migrated to the Port Elizabeth townships in the 1950's to seek employment. Many grandmothers came from Kokstad and surrounding districts.

The group agreed on the fact that most grandparents were sickly and most suffered from hypertension, diabetes and arthritis. Many were caring for grandchildren who were also ill from HIV related illnesses. Most were in a stressed state and were constantly concerned about their inability to provide for their grandchildren's basic needs. Most were older than sixty years, unemployed and dependent on income from state pensions and grants. Most grandparents were widowed and had no life partner. Most grandmothers were worried about the future of their grandchildren after their death.

4.2.2.3 Ways in which grandparents access services of supporting agency

Lulu explained that there were a few goGogetters in each township who served the community in which they lived. These gogos marketed the programme in their respective churches, at Stokvels, at pension paypoints where they invited other gogos to become involved in the programme.

Sharron explained that it was through a combination of the GoGo Trust reaching out to grandparents and the grandparents seeking help from the programme. She mentioned that as the programme's profile in the township increased mainly through word of mouth, gogos in the community would contact the GoGo Trust's project manager and ask for assistance. One of their community leaders was also given the task of identifying gogos who were in need of emotional and spiritual support.

Pastor Banzi said that they were planning to announce the *Kingdom Women in Leadership* programme during their church services and market it through other projects run by the church. One of their projects which had proven to be successful was providing sports coaches to schools in the township and co-ordinating leagues for soccer and netball teams which had been established in the primary and high schools in Motherwell. He mentioned that they would reach the gogos via the children participating in these sports. He added that the coaches of soccer and netball teams also reported cases of need to them and some of the coaches even brought their entire teams to church on Sundays.

Mama Florence said that everyone in her street knew about the Tuesday meetings and knew that her door was open to everyone.

4.2.2.4 Needs of grandparent-headed households that supporting agencies are presently unable to meet

Pastor Banzi mentioned that one area in which they were not being effective was in protecting gogos from abuse and exploitation at the hands of their own relatives. He illustrated this point by describing how some relatives opened credit accounts at furniture stores using the gogo's identity document and purchasing furniture for themselves and neglecting to pay the monthly instalments. Some borrowed money from companies with whom the gogos had taken out funeral policies and neglected to repay these loans. He was also frustrated by the corruption of government officials who syphoned money from the coffers of pensioners. His church had also not been able to address the issue of the *skoppers* (loan sharks) which he described as a cancer. Lulu spoke about the fact that goGogetter workers were seen as a threat to perpetrators of child abuse in the community and some had even been intimidated by these alleged abusers and instructed not to return to these communities. She also spoke about the fact that many gogos were resistant to the perceived interference of the goGogetters who sometimes tried to advocate on the orphans' behalf when the gogo was being too harsh in disciplining her grandchild.

Most participants felt that the financial needs of grandparents caring for orphaned grandchildren, was one that they were not able to address satisfactorily. Sharron tried to put this issue into perspective by explaining that when the parents of the orphans died and the grandchildren came to live with their grandparents, the household expenses doubled, tripled and in some cases quadrupled. She gave an example of a family in King William's Town where the parent died of AIDS and six children just arrived at the grandmother's doorstep in Kwazakhele, all needing care. The best they could do was to help the gogo access government funding which took them eighteen months to achieve but which in itself was hopelessly inadequate. They also tried to help families by teaching the orphans marketable skills with which they could generate additional income but still these efforts did not provide for the real financial needs of these grandparent-headed families.

Sharron referred to the immense grief in grandparent-headed households as one of the biggest challenges where grandparents were dealing with the loss of their own children and the grandchildren trying to cope with the loss of their parents. She said, "I think the biggest challenge is to keep the children in a place of hope and keep them forward-looking. When they begin to lose hope, they lose purpose and fall into a life of crime or immorality." She added that a need even greater than the financial need was for the members of grandparent-headed families to know that there were people who genuinely cared about what was going in their homes on a day-to-day basis.

4.2.2.5 Qualities necessary for personnel working directly with grandparent-headed households

Lulu believed that people doing this work should be genuinely interested in the community and should know the community in which they worked. They should have a passion for young people and be able to communicate with them and preferably be a gogo themselves, in her opinion. Such a person should be assertive and be able to deal confidently with stakeholders. She should be a role model in her community.

The group came to the conclusion that personnel working directly with grandparent-headed households should understand the value of people and be good listeners. They needed to be committed and disciplined. They needed to have a financial base that they could draw from to bring on-the-spot assistance when it was needed. Possessing a creative skill such as sewing or pottery which could be imparted to gogos and children and which could generate income for them would also be a useful quality. Sharron emphasised the fact that commitment, in her view, was the most important quality.

4.2.2.6 Lessons learnt to date with regard to supporting grandparent-headed households

I asked the group to think about the biggest lessons they had learnt while being involved in supporting grandparent-headed households. Sharron mentioned that gogos and orphans alike needed to know that there was some purpose to the suffering that they had endured. She spoke of a gogo who once said to her, "We feel forgotten". Sharron said that she was trying to understand the broken-heartedness in people so that they could progress from a place of hopelessness to a place of hope and life.

Pastor Banzi had learnt that gogos were very proud and often said that they understood what was being asked of them but often did not. Lulu identified with Pastor Banzi's point and said that she had learnt to approach gogos in a loving, respectful way. She added, "If you judge them wholesale they clam up." She had learnt that gogos possessed a lot of wisdom and once they felt respected and acknowledged they were willing to impart their wisdom.

Pastor Banzi shared that he had learnt the importance of keeping his word when working with gogos. He said, "They will not do what you've asked until you do what you promised them you would do."

Lulu had learnt that gogos learnt new concepts through drama and role playing rather than through lectures and speeches. She said, "Their concentration span is very limited, so when you do things with them, keep it short." She also firmly believed that the key to fighting the scourge of HIV/AIDS was utilising grandparents in the community to spread the word and to be mentors to young people, even those who are not related to them.

4.2.2.7 Recommendations to agencies contemplating offering this type of service

The group came up with the following recommendations:

- Do not re-invent the wheel. Do some research and find out who else is doing this kind of work and learn from them and network with them.
- Do not only see gogos as the recipients or beneficiaries of the programme. They are key people who can add value to the programme and have much to offer. Make use of their wisdom.
- Adopt a hands-on approach where you just go to these shacks, take them food and clothing, sit with the grannies and listen to the story and become committed to assisting them in helping their grandchildren to become everything they would desire them to be.
- Orphans and vulnerable children know what they need so ask them.

4.2.2.8 Support needed by agencies

Income to sustain their respective programmes appeared to be the common need amongst the stakeholders. Another was training. Pastor Banzi listed the following training needs for the staff involved in the *Kingdom Women in Leadership* programme;

- Counselling skills
- Management
- Communication
- Human relations
- Behaviour management

The participants also mentioned the need for a resource library that they could access when information was needed.

4.2.2.9 Synthesis and conclusion of focus group

The stakeholders presented as genuine, selfless leaders without hidden agendas. They all have a passion for this work and a real empathy for grandmothers and their orphaned grandchildren. A significant point that emerged was the exponential effect that is created when grandmothers become leaders over other grandmothers. Many more grandparent-headed households are reached in this way. The importance of meeting the physical, spiritual and psychological needs of the grandmother-leaders

was highlighted as being essential to them being effective in meeting other grandmothers' needs. The point that orphans in grandparent-headed homes have their own set of issues and needs and warrant a dedicated programme to meet those needs was also raised. Recognising that grandmothers are key role players in the fight against AIDS as opposed to being passive recipients of services was a significant point.

I learnt that grandmothers are definitely teachable but one needs to understand how they learn. The point that agency staff members involved in this type of programme also require training was well made.

It was pleasing to observe how the stakeholders exchanged contact details after the focus group indicating that some form of networking was about to take place.

In doing the data analysis the following categories emerged: the support role of churches; government support and involvement in grandparent-headed households; stressors and needs of grandparents; stressors and challenges for grandchildren; empowering grandmothers; challenges with regard to working with grandmothers; resilience of grandmothers.

4.2.3 Orphans group

I enquired at the end of the first focus group which grandmothers had orphaned grandchildren between the ages of fourteen and nineteen in their care and asked if they would invite them to this focus group. I also asked the co-ordinator of an organisation offering support to grandparent-headed households to invite at least two orphans in this age group to the focus group. The group consisted of six participants, four of whom were from Motherwell and two were from the township of Kwazakhele in Port Elizabeth. I conducted the focus group in the same venue in which the grandparent focus group was held. Everyone present was conversant in English.

4.2.3.1 Biographical profile of orphans

Once again the respondents' names have been replaced by pseudonyms to ensure their confidentiality.

Nompumelelo is nineteen years old and has lived with her grandparents all her life. Her mother died in 2009 from AIDS after having been ill for five years. She does not know her father. She passed grade twelve at the end of 2009 and is currently looking for employment but wished that she had the means to go to university. Nompumelelo's aunt (her late mother's sister) passed away within months of her

mother's death - also from AIDS - and her daughter (Nompumelelo's cousin) is also in the care of their grandparents.

Phumulo is seventeen years old and has also lived with his grandmother since birth. Both his parents are alive but neither have any involvement in his life. He is currently in grade nine at a school in Motherwell and is the only child living with his grandmother.

Gift is nineteen years old and in grade ten at a school in Motherwell. His mother is still alive but she plays no role in Gift's life. He does not know his father. Gift has lived with his grandmother all his life. He has an older brother who lives independently.

Zanoxolo is fifteen years old and is in grade seven at a primary school in Motherwell. He moved in with his grandmother four years ago after his mother was killed in a motor accident. He knows his father's whereabouts but he unfortunately does not take an interest in Zanoxolo's life. He has no siblings.

Siyanda is eighteen years old and is in grade twelve at a school in Kwazakhele. He has lived with his grandmother, who is sixty four years old, all his life. His mother passed away in 2005 from an AIDS related illness when he was in grade seven. Apart from his granny, he shares the house with his maternal aunt and cousin. He plans to study pharmacy at Nelson Mandela Metropolitan University next year if his application for a bursary is successful.

Pumlani is seventeen years old and is in grade ten at a school in Kwazakhele. He has lived with his grandmother since he was eight years of age. Before that he was raised by his great grandmother in an Eastern Cape town called Hankey. His mother passed away in 2002 and his father in 2009, both from AIDS related illnesses. He shares the home with his grandmother, maternal aunt and two younger cousins. He wants to become a commercial pilot when he completes grade twelve.

4.2.3.2 Living conditions

Nompumelelo lives in a three-roomed shack. She shares one of the bedrooms with her cousin while her grandparents stay in the second bedroom. They have water and electricity supplied to their shack and make use of an outside toilet. The lounge also serves as the bathroom where a bucket is filled with water that has been boiled in the kettle.

Phumulo shares a one-room shack with his grandmother. A curtain across the centre of the shack provides a measure of privacy to both. They have electricity supplied to their shack and the tap outside

gives them access to running water. They also use an outside toilet. There is no hot water geyser and water has to be boiled in the kettle for bathing purposes.

Gift and his grandmother also share a single-room shack. They have electricity supplied to their shack and make use of an outside toilet. The tap outside gives them access to running water.

Zanoxolo mentioned that his living conditions were similar to those of Gift.

Siyanda explained that he lives in an *EDP house* in Kwazakhele which is different from an RDP house. These are evidently houses that were built in the 1980's by the Apartheid government. They have electricity and water in the house but the toilet is situated outside.

Lungile lives in a shack with his grandmother (*Makhulu*, as he calls her) but does not have electricity or water supplied to his dwelling.

4.2.3.3 Aspects of life with their own parents they longed for the most

Phumulo, whose own parents had not been involved in his life, began this discussion by mentioning that he felt nothing and that he had learned to shut out any memories of his mother and father from his thoughts. He described it as "an empty space".

Nompumelelo had more positive memories of her mother and said that she missed her mom's voice. She longed for her mother's counsel and advice which she was given after she had done something wrong. She missed her mother's discipline.

Zanoxolo also missed his mother's voice and said that it felt so good when he remembered his mother speaking to him.

Siyanda shared that his mother had a good sense of humour and that he missed her jokes most. He added that his mother was very caring and that she stood up for him when other adults criticised him.

Pumlani said that he missed everything about his mother. He was her only child and she provided everything he needed until she took ill in 2001 and died in 2002. "After that money came through my grandmother," he said.

4.2.3.4 Counselling and emotional support received subsequent to parents' death

All the participants agreed that young people who had lost their parents needed emotional support and counselling but their experiences at the time of their loss were varied. Nompumelelo, for instance, explained that this had been a very difficult time for her because she had just started her matric year when her mother was in the final stages of her illness and tried to cope with the pressure of schoolwork whilst also grieving the loss of her mother. She received no emotional support or counselling at the time or at any stage subsequent to her mother's death.

Pumlani said that a social worker from the Department of Social Development spoke to him and gave him emotional support after his mother died.

Phumulo mentioned that he received some support from his maternal aunt who spoke to him about his mother.

Zanoxolo's grandmother was his source of strength and comfort after his mother passed away.

Gift said that his older brother allowed him to speak about his feelings regarding his absent parents.

Siyanda spoke of his mother being his support because she was so strong but after she died "the pain was inside and I just moved on," he said. He received no counselling after his mother's death.

4.2.3.5 Appreciation of grandparent caregivers

I asked the group to consider what they appreciated most about their grandparents.

Siyanda said, "Her love and care for me. I thank God that He keeps her from dying now. When I'm older I can show her how much I appreciate her. Gogo really cared well for my mother when she was so sick."

Phumulo was thankful that his grandmother looked after him and said that he tried his best to obey her and respected the rules of the home. His grandmother always knew his whereabouts.

Pumlani said, "I appreciate everything she's done for me. She makes it possible for me to be at school. She allowed me to come from Hankey to stay with her. She provides all my needs. She supports me as a mother would. When I grow up I also want to do good things for her to show her how much I love her." He added that he was very thankful to his grandmother for attending PTA meetings and meeting with his teachers to discuss problem areas.

Nompumelelo appreciated the fact that her grandparents were there for her. Referring to her grandmother she said, “She’s like an anchor in my life.”

Gift was most appreciative of his grandmother’s encouragement. He said, “She encourages me to strive for better, not to go backwards in life. She encourages me to go to church.”

Zanoxolo was grateful to his grandmother for taking care of him and meeting his basic needs.

4.2.3.6 Challenges with regard to being raised by elderly grandparents

Phumulo wished his grandmother would trust him more. “She’s always suspicious about girls,” he said.

Gift had a similar complaint. He said, “If I had a mother or father to talk to they would understand me better. My gogo is too old-fashioned and doesn’t talk about sex or relationships.”

Nompumelelo disagreed and mentioned that her grandmother spoke quite openly to her and her cousin about sex and HIV/AIDS and felt that she was not losing out on anything because of her grandmother’s age. “She’s doing as well as my mother would have,” she said.

Phumulo wished his grandmother had more energy so that she could be more involved in his school life and in his sporting activities. He conceded that he had gotten away with many things because he was physically stronger than his grandmother and said that his mother would have challenged him more than his Gogo did.

Zanoxolo stated that due to his grandmother’s limited income (from the grant she received) there was no money for extras like clothes and shoes.

Siyanda agreed with Zanoxolo and said, “You don’t get all the things that children with mothers get. Like with clothes, I get all the cheap stuff. I can’t get a computer because there isn’t money for one. But all the love and care is there.”

Pumlani added that he also missed the nice things that he used to get when his mother was alive.

4.2.3.7 Support offered by orphans to their grandparents

I directed the discussion to ways in which they were able to help their grandparents in the home.

Siyanda said, "I tell her I love her. When she has asthma I bring her her medication. When her ankles are swollen I rub her feet with ointment. On weekends I clean the yard."

Phumulo said that he also regularly cleaned the yard for his granny.

Nompumelelo mentioned that she had given her grandmother flowers on Mother's Day and also for her birthday. On a daily basis she volunteered to cook and clean the house.

Zanoxolo explained that he did *odd-jobs* over the weekend and during the holidays to supplement the family income. He had been taught to do plastering of walls and was employed on a part-time basis by builders. He said that he bought "whatever is short in the house" with the money he earned. He also helped to clean in the house.

Pumlani said that he did the cooking sometimes, cleaned the house and did anything his grandmother asked of him to show her how much he loved her.

Gift made sure that the porridge was cooked before he left for school each day. On weekends and during the holidays he did the washing for his grandmother. He said that sometimes he rubbed her legs when she was in pain. He also accompanied his grandmother on her monthly visits to the clinic.

4.2.3.8 Areas in which orphans felt they could do more for their grandparents

Nompumelelo dreamt of building a big house for her grandparents and buying them a car but presently was doing all she could to help them.

Phumulo felt that he could do more for his grandmother by caring for her when she was sick but said that he was too busy playing sport. He was really serious about playing soccer and hoped to earn good money from playing professional football one day so that he could buy a proper house for his grandmother.

Gift said that he worried a lot about his grandmother's health and struggled to concentrate at school as a result of this. He explained that on a daily basis he prepared his grandmother's medicines for her to take while he was at school but he wished he could do something about reminding her to actually take her medicine. He also felt bad that he could not rub her legs while he was at school.

Pumlani said that perhaps he could help more by doing the washing sometimes.

Siyanda wanted to succeed in life so that his grandmother would be happy. He wanted to provide for her and that when she died that she would have peace of mind knowing that his future was secure.

4.2.3.9 Orphans' perception of elderly caregivers' greatest challenges

The participants were unanimous in identifying their grandparents' financial constraints as their biggest challenge. Their grandparents sometimes borrowed money in order to provide for their grandchildren's needs and even made personal sacrifices, like not buying clothing for themselves, so that they (the grandchildren) would not have to go without. Equally challenging, according to most participants, was their grandmothers' health problems. All their grandmothers suffered from diabetes and high blood pressure and one grandmother was asthmatic. Siyanda mentioned that his grandmother had severe pain due to her arthritis.

4.2.3.10 Orphans' views regarding the assistance that grandparents require from supporting agencies

I asked the group to consider aspects that an agency should focus on if it wanted to provide meaningful support to grandparent-headed households.

Nompumelelo said that her gogo needed counselling because "she doesn't understand why my mother passed away. She needs help with the grief of losing her daughter."

Both Phumulo and Zanoxolo felt that an agency should help their grandmothers get more financial aid from the government so that they would have enough money to take care of them.

Gift also mentioned the aspect of finances for his grandmother and spoke about the need to find someone to take care of him after his grandmother passed away. He explained that his grandmother was stressed about what would happen to him after her death.

Siyanda and Pumlani both thought that being part of a support group, which an agency could facilitate, would be beneficial to their grandmothers.

4.2.3.11 Orphans' unmet needs which supporting agencies should consider

The discussion focused on their need for finances once more. They all needed money to continue with their education.

Nompumelelo's point was significant, in my view. She mentioned that she needed an agency to take care of her grandmother by counselling her, helping her clean her house and getting her to the clinic so that the burden of caring for her grandmother could be lifted and she could pursue her own dreams and enjoy peace of mind knowing that her grandmother was being cared for.

4.2.3.12 Synthesis and conclusion of focus group

Most participants in this focus group were orphaned because of HIV/AIDS. The absence of fathers in these young people's lives was a striking revelation. The very poor living conditions which all of them are subjected to makes one realise how poverty and HIV/AIDS are inextricably linked. One also realises how learning is compromised when scholars return from school each day to a home that is not conducive to studying. Despite their hardships all the focus group members expressed sincere appreciation to their grandparents for the nurturing role they were playing in their lives and all felt a need to express their appreciation to them in some tangible way which would lighten their grandparents' load. It was interesting to hear them mention that their desire was to achieve success in life in order to give their grandparents peace of mind. It was heartrending to hear orphans express their longing for their mother's voice. The need for grief counselling for orphans as well as for their elderly caregivers was highlighted once more in this focus group. Even young people appreciate the value of support groups for grandmothers. It also became evident that there is a significant communication gap between these two generations but despite this, they were able to live with each other in a relatively amicable way.

4.2.4 Summary of all three focus groups

One key factor that resonated through all three focus groups was the key role that grandparents are playing in responding to the orphan crisis in our country. There does not appear to be sufficient recognition from government and society in general of the magnitude of their task in caring for orphaned children. It was evident that grandparents in the main are hopelessly under-resourced and are in dire need of support in the form of adequate housing, sufficient funding, proper health care, emotional and spiritual support, protection from abuse by relatives, training in managing children's behaviour and in financial management and permanency planning for orphaned grandchildren if they are going to be a sustainable option as far as providing for the needs of orphans is concerned. The resilience of the members of grandparent-headed households was evident in all three focus groups. All three focus groups highlighted the fact that children and grandparents have a number of common issues but each have unique needs which should be responded to separately

4.3. CASE STUDIES

4.3.1 Case study one: Grandmothers Against Poverty and AIDS (G.A.P.A)

My first case study would be categorised as a study of an organisation. In the course of doing my literature study I came across a Cape Town-based organisation called Grandmothers Against Poverty and AIDS. Since I am an itinerant trainer in the field of child and youth care I often travel to other centres in South Africa. My work commitments took me to Cape Town in August 2010. I seized the opportunity and set up an appointment to visit G.A.P.A. in Khayelitsha, outside Cape Town. I conducted a semi-structured interview with the present executive director of the organisation, Vivienne Buduza as well as with the programme director, Althea Barry.

4.3.1.1 Genesis of the organisation

G.A.P.A. started in October 2001 as a self help pilot project in the township of Khayelitsha. It was founded by Kathleen Broderick who while busy with her master's research on the subject of HIV/AIDS worked very closely with grandmothers in Khayelitsha who became so attached to Kathleen that they begged her to stay. Kathleen eventually raised sufficient funding and secured land on which to build the multipurpose centre which was opened in January 2004. Vivienne has been part of the programme since its inception and became the executive director in 2007. She was previously an adult trainer in the Health Department of the Cape Town Municipality.

4.3.1.2 Involvement with grandparent-headed households

G.A.P.A. runs workshops for grandmothers in Khayelitsha that are facilitated by trained grandmothers. They are conducted in isiXhosa and concentrate on topics such as: human rights, HIV/AIDS, elder abuse, writing a will, parenting skills, vegetable gardening, nutrition, healthy ageing, bereavement, business skills and how to access government grants.

There are presently twenty five active peer support groups that meet in group leaders' homes every week. In these meetings grandmothers offer each other advice, friendship and emotional support. Once grandmothers are emotionally strong they are invited to form co operative groups which concentrate more on income generation.

G.A.P.A. runs groups where grandmothers are taught handicraft skills like sewing, crocheting, knitting and carpet making.

G.A.P.A. assists grandmothers in starting up their own home-based enterprises and sometimes the organisation is contracted by external agencies to supply handicraft. G.A.P.A. grandmothers are able to supplement their income by doing some of the contract work which usually involves manufacturing handicraft items.

G.A.P.A. grandmothers receive a subsidy from the programme for the schooling of their dependents. Their orphaned grandchildren are then able to receive pre-school education and the grandmothers are free to take care of their personal needs.

G.A.P.A. grandmothers also run an aftercare enrichment programme from the children's centre on the organisation's property in Khayelitsha. It is specifically geared toward primary school children made vulnerable by the absence of their parents.

4.3.1.3 Profile of grandparents involved in the programme

Althea explained that most are widowed, isiXhosa speaking and older than fifty years of age. They have between one and three chronic health conditions including diabetes, osteoporosis, hypertension and arthritis. There are some who are cancer sufferers, specifically with breast and cervical cancer. Almost all are on medication and all have been affected by HIV/AIDS. Poverty is the biggest element in their lives and those older than sixty years receive an old-aged pension. Many receive child support grants from the state. Most have more than five mouths to feed. Most are literate and have completed between six and eight years of schooling. Many suffer from Post Traumatic Stress Disorder as a result of rape and other trauma that they have been subjected to even during their own childhood. Most have chronic depression. Althea said that it was common for a granny to say, "I am on sleeping tablets." She also mentioned that all gogos had experienced death in their families. An interesting point she made was the fact that most grannies approached G.A.P.A. because of poverty but in the process of being helped HIV/AIDS became a factor. She stressed the fact that there is a strong link between HIV/AIDS and poverty. In a support group of seventeen grandmothers, at least fifteen of those had lost their partners when they were newly married. Althea explained that their partners were possibly migrant workers, were abusive to their wives or they were forced into marriages with these men. Sometimes they felt empowered enough to leave their husbands when circumstances became unbearable.

4.3.1.4 Grandparents' greatest challenges

Poverty was mentioned as the single most difficult challenge for grandparents. An average grandparent-headed home had between five and fourteen grandchildren whom the grandmother had to provide for from her pension of R1080. Grandmothers younger than sixty years of age did not receive a pension and some relied on a foster grant of R640 while others only received a child support grant of R210 per month.

Another challenge for grandmothers was that many of their grandchildren did not have birth certificates which prevented them from applying for a government grant. Grandchildren were often “dumped” with the maternal grandmother after the death of the mother and left without any documents.

There was also an expectation that the grandmothers should care for the grandchildren even when the parents were alive and parents regarded it as their right to have access to the grants.

A common phenomenon was that of teenage granddaughters ‘dumping’ their offspring with their grandmother and using the child support grant for their own personal needs.

Althea often heard complaints from gogos that their grandchildren demanded money from them for perceived luxuries such as designer clothes and hair products.

Grandparents, according to Althea, obtain meaning from being nurturing parents but this aspect was often exploited by young people in grandparent-headed homes.

Helping grandchildren with homework was described as a challenge for grandmothers given their limited education. Talking about sex to grandchildren was also perceived by grandmothers to be a taboo subject and extremely difficult to do.

4.3.1.5 Successes

Vivienne believed that the various projects that G.A.P.A. was running had proven to be successful and they were proud of the work they had done to date. The psychosocial support that grandmothers received through the support groups was one they felt really added value to the lives of gogos in Khayelitsha.

They were proud that G.A.P.A. had been allocated a stall at the Greenpoint Stadium where they sold gloves that had been knitted by grandmothers in the colours of the teams represented at the FIFA World Cup Tournament.

They were proud that they were represented at the International Grandparent Conference sponsored by the Stephen Lewis Foundation in Swaziland earlier in 2010 by a few gogos from the programme. Some G.A.P.A. grannies even attended the International Conference in Canada in 2006. When they returned from the conference, one granny had evidently proudly remarked that they had “crossed the Red Sea”.

The G.A.P.A. model has been lauded by an international funder who wanted it to be replicated in Tanzania. In fact stakeholders from Tanzania visited the programme in Khayelitsha in 2008 and learned about the mechanics of running such a programme and a number of granny support groups have since been established in that country.

4.3.1.6 Limitations

Vivienne mentioned that their limited finances were their biggest obstacle. They had tried to create an emergency relief fund for crisis situations they encountered but this fund was currently depleted. Althea said that poverty had taken its toll on them as an organisation. She mentioned that the Department of Social Development had even asked them to stop referring cases to them.

When a granny complained that her cupboards were completely empty, G.A.P.A. staff would dip into their own pockets on occasion to provide basic food supplies to these desperate situations. Althea also mentioned that HIV/AIDS had taken its toll and that 2010 was the year in which they were hardest hit.

An alarming fact was that a grandparent working in the aftercare centre, where she cooked for the children, often went home not being able to provide food for her own grandchildren.

Althea explained that G.A.P.A. did not involve itself in family dynamics but referred such cases to the Department of Social Development for social work intervention.

4.3.1.7 Needs of orphaned grandchildren

Grandparents in the programme are taught to provide the following nine basic human needs:

- Safety/security
- Affection
- Creativity
- Identity
- To be alive

- To be understood and to understand others
- To participate
- To relax and have fun
- Freedom

Staff members understand that most of the grandparents were not able to experience these needs themselves as children and make efforts to ensure that as grandparents they have opportunities to experience them now.

4.3.1.8 Qualities needed to do this work effectively

- Both Althea and Vivienne emphasised that the primary quality needed was passion for the work.
- A strong appreciation of what grannies are able to do and to have confidence in them.
- To understand that one is able to reach grandparent-headed households by reaching out to grannies.
- To know the community profile and to be aware if this programme was relevant or not.
- To have a sound knowledge of developmental theory.
- To be servant-hearted.
- To be creative.
- To know when it is time to let go and hand over the reigns to someone else.
- To have self awareness.
- To be humble.

4.3.1.9 Recommendations to agencies contemplating offering this type of service

- There is wisdom in doing thorough research before launching such a project.
- Always consult grannies and never assume that you know why they have chosen a certain path – for example, why she has not taken a child to the clinic.
- Do not be autocratic.
- It is a wrong assumption to believe that such a programme should be run by a teacher or a clergyman.
- Do not be ambitious and set your sights too high. Progress is slow sometimes.

- Encourage orphans to accompany their grandmothers to the workshops so that if and when she passes away the skills remain within the family and in the meantime a network of support is established for the orphans.
- Be mindful of ethical issues like confidentiality because grannies are aware of their rights.
- Do not make false promises to grannies, especially when you start the project. They will adopt a wait and see attitude until you have won their trust.
- Do not set precedents from the offset that you will not be able to carry through.
- Keep in mind that people will approach the organisation with private agendas and sometimes feign commitment to the work when in fact they are there to meet their own survival needs, but carry on regardless.
- Grandmothers benefit from education and support.
- When grandmothers are empowered they have incredible value and can make a huge difference in the fight against HIV/AIDS and poverty.
- Grandmothers have done amazing work in reducing the stigma of HIV/AIDS and have encouraged many people to get tested and to access treatment. Consider using them to speak to university students and even to address parliament about the realities of being affected by HIV/AIDS.
- Find a funder who understands the work you are doing and is willing to invest in your concept and be committed to it.

4.3.1.10 Needs of Organisation

- Money
- Material that can be utilised for income generation projects e.g. off-cuts from factories.
- They need their building to be extended and an architect who is willing to design the building because grannies sometimes have to sit outside because there is insufficient room.
- They require material for their vegetable gardening project e.g. seeds, manure, shade-cloth.
- They require a dedicated vehicle for conveying grannies to meetings.
- They also need a utility vehicle to transport groceries and donated goods.
- They need more office space and a board room facility.

4.3.1.11 Synthesis and conclusion of interview: case study one

G.A.P.A. is making a significant difference to the lives of grandparents in Khayelitsha. For a relatively small non government organisation they have a huge footprint in the field of caring for grandmothers. They have recognised the needs of grandparents caring for orphaned grandchildren and have responded effectively in meeting those needs through the various programmes on offer. They empower grandparents to become more self-sufficient and teach them to be more entrepreneurial in generating income for their homes. Their support groups are absolutely vital to the well-being of grandparents and have mushroomed throughout Khayelitsha. They network very effectively with other organisations and have even connected with international organisations doing similar work. The staff members are highly professional and have a real passion and empathy for grandparents and deserve much more recognition and financial backing for the sterling service they provide to grandparent-headed households in Khayelitsha. It comes as no surprise that their model is being replicated elsewhere in Africa.

4.3.2 Case study two: Mama Sophie's family

I conducted a semi-structured interview with this family and used the *social group case study method*. After my interview with Vivienne and Althea from G.A.P.A., I asked them to identify a grandparent-headed family consisting of orphaned children between the ages of fourteen and nineteen who were available and willing to be interviewed during the week that I was in Cape Town. Once again the respondents' names have been replaced by pseudonyms to ensure their confidentiality. The interview was conducted in Mama Sophie's home in Khayelitsha on 18 August 2010.

4.3.2.1 Biographical profile of Mama Sophie's family

Mama Sophie is sixty three years of age, and the head of a family consisting of an adult son, four grandchildren and two great grandchildren. She had eight years of formal schooling. Her daughters passed away in 1999 and 2002 respectively from AIDS. Her husband passed away in February 2001. Both daughters had two children each and the two granddaughters aged twenty two and nineteen respectively have had a child each. The great grandchildren are four and three years of age respectively. Mama Sophie explained that "it was just normal" that she would take care of her grandchildren when their mothers passed away because they were all living together in the same house at the time of their death and there was no one else to take care of the grandchildren. "Their mothers are my daughters, my blood," she said.

4.3.2.2 Living conditions

The family lives in a three-bedroom dwelling in Khayelitsha Township outside Cape Town. The family of eight sometimes have two other relatives staying with them. They have electricity in the house but the pre-paid meter regularly 'ran out' long before there were finances to top it up again and the family resorted to using candle light. There is an outside toilet and they have water supplied to their home but there is no hot water geyser.

4.3.2.3 Financial situation

Mama Sophie is the sole breadwinner in the home. She receives a pension of R1080 per month and also earns a small stipend of R750 per month for the work she does at the G.A.P.A. aftercare centre. Mama Sophie said that this money carried them through to about the middle of each month. "After that we've got nothing and there's no bread even now," she said. When asked how they survived for the rest of the month Mama Sophie replied, "God is making our stomachs full." One of the granddaughters mentioned that they were always borrowing money and paying it back. The granddaughters each received a child support grant of R250 for their respective children.

4.3.2.4 Health status of grandparent

Mama Sophie said that she often experienced pain from the arthritis in her hands but apart from that she was well.

4.3.2.5 Positive aspects to caring for grandchildren

Mama Sophie shared that her grandchildren were looking after her now. She illustrated her point by mentioning that her grandchildren helped her find things when she had misplaced them and they cooked for her sometimes.

4.3.2.6 Challenges with regard to caring for grandchildren

Mama Sophie regretted the fact that she did not have the means to give her grandchildren everything they wanted and needed. "Sometimes they see other kids with nice shoes but I haven't got money to make them happy," she lamented. She added that it was hard for her that she could not afford to pay for her granddaughters' tertiary education. Pointing to her granddaughter she said, "When I die she must know what she must do. I'm worried about my grandchildren's future especially after I've passed on."

4.3.2.7 Support system

Since her extended family lived in the Transkei, Mama Sophie said that G.A.P.A. was her only support system. She spoke of the support she received from the other gogos involved in the G.A.P.A. programme when her daughters died. "We are sharing our problems with others in the same situation and we realise that there are others with the same or even worse problems than our own. It makes me feel better inside," she said.

4.3.2.8 Resilience factors

When asked what kept them going as a family despite their hardships, they acknowledged that God, through G.A.P.A. was a huge source of strength to them. Mama Sophie said, "I know that God is looking after me. When I pray I find that God answers my prayer and not long after that someone comes and gives me R20." One of the granddaughters mentioned that they did not put undue pressure on their granny when there was no food. "We don't give her a hard time; we just accept there's nothing." She said. When asked how they would cope as a family without Mama Sophie one day, one of the granddaughters responded, "We will try to survive. We will help each other like we do now. It doesn't matter which child belongs to who, we all just do our part."

4.3.2.9 Talking about sex and HIV/AIDS

Sex is a taboo subject in the home. Mama Sophie explained that she was too shy to speak about it to the grandchildren. "At school they learn about it, even seven year-olds know what is going on," she said. Even when Mama Sophie's daughters were gravely ill they evidently never, as a family, spoke openly about HIV/AIDS.

4.3.2.10 Experience of losing a parent

One of the granddaughters responded by saying, "At first I didn't know she's sick with HIV/AIDS. I didn't know about these things. When I found out the truth I just broke down, I couldn't take it. I didn't put my attention to it – I couldn't believe it. But as the days went by I was acting as normal, as though she's got flu. There was nothing I can do. Then she died." She explained that she needed to speak to someone about her feelings with regard to losing her mother but she said that could not because she did not know whom to speak to.

4.3.2.11 Positive aspects to being raised by a grandparent

The granddaughters mentioned that their grandmother's knowledge, wisdom and life experience was what they appreciated most.

4.3.2.12 Challenges with regard to being cared for by an elderly caregiver

The physical lack of resources seemed to be the biggest challenge. There simply was not enough money in the home to have all their needs met. "Sometimes I wish my mother was here to give me something my granny can't," the one granddaughter said.

4.3.2.13 Future goals

The granddaughters' biggest desire was to study further so that they could get good jobs and earn decent salaries. They mentioned that they were tired of sitting around.

4.3.2.14 Synthesis and conclusion of interview: case study two

By conducting this interview in Mama Sophie's home in Khayelitsha I came face-to-face with the conditions of poverty that she and her family were living under. I was struck by the family's sense of resignation to the reality of this being their lot in life. The interview revealed how significant the role of G.A.P.A. was in sustaining this family. Mama Sophie's absolute faith in God and in His provision was astonishing. A real concern was the fact that the subject of sex was never addressed in this home and that two adolescent girls had become mothers. The fact that sex was a taboo subject even in the context of a home where two adults had died from AIDS made me realise that this aspect seriously needed to be addressed. It also appeared that the emotional and psychological needs of the orphans in this home had not been adequately addressed.

4.3.3 Case study three: Mama Joyce's family

On another of my training assignments I was working at a facility in Johannesburg called *Cotlands* and discovered that they had an outreach programme to grandparent-headed households run from their satellite office in Soweto. I asked them to identify one of their families with whom I could conduct an interview. They selected Mama Joyce's family and one of their home-based health care workers accompanied me to her home in Meadowlands for the interview on 17 September 2010. I conducted a *semi-structured interview* with this family and used the *social group case study* method. Once again the respondents' names have been replaced by pseudonyms to ensure their confidentiality.

4.3.3.1 Biographical profile of Mama Joyce's family

Mama Joyce is sixty three years of age, has never been married. The father of her children had recently passed away but they had been separated for many years before that. She has had four years of formal schooling. She lost three adult children to HIV/AIDS and fulfils the parent role to her two grandsons, aged seven and fourteen, her late daughter's children who are both HIV positive. The fourteen year old grandson is a special needs child and attends a special school. Mama Joyce's two surviving daughters also live with her. There are two other family members, Mama Joyce's niece and nephew who often stay over at her home.

4.3.3.2 Precipitating factors leading to grandparent fulfilling parent role to grandchildren

Mama Joyce's late daughter had her own home in Meadowlands until she took ill and then moved in with her mother together with her two children. The daughter was pregnant when she moved in with Mama Joyce. The two children were very sickly at the time also. At the time they did not know that her daughter had AIDS. Mama Joyce's daughter gave birth to a baby girl who passed away a few hours after being born and she herself passed away four days later. Mama Joyce had no option but to take care of her grandchildren because there was no one else in a position to do so.

4.3.3.3 Living conditions

The family lives in a converted container which was provided by Cotlands through funding from the Italian government. The container provides approximately twelve squared metres of living space which consists of two sections – a bedroom and a living area which serves as a kitchen, lounge and bathroom. There is an outside toilet and they get water from a communal tap outside. They do not have electricity because the area where they live has not been formerly zoned as a residential area and the Johannesburg municipality has evidently refused to provide electricity to these residents. They use paraffin for cooking purposes and use candle light when it gets dark.

4.3.3.4 Financial situation

The only source of regular income is from the child support grant which Mama Joyce receives for her two grandsons amounting to R500 per month. Her daughter has part-time work at a wholesaler and is occasionally able to contribute a small amount. The R500 has to provide for everyone in the home, not just the two grandchildren.

4.3.3.5 Health status of grandparent

Mama Joyce described her health as follows, “I’m very sick. When I go to sleep I feel like I won’t get up, that I will die. I’ve got too much headache and I’ve got pain here and here (pointing to her side and back). I was thinking I’ve got high blood but the clinic do tests and they say I haven’t got high blood and I haven’t got sugar. But I feel sick; I’m not fine for eight months now.” She said that she used home remedies that she got from her church.

4.3.3.6 Positive aspects to caring for grandchildren

Mama Joyce said that her one grandchild was not difficult.

4.3.3.7 Challenges with regard to caring for grandchildren

Mama Joyce found it difficult when the elder grandson demanded “nice things” like a watch and designer shoes. She found it frustrating when her grandchildren wanted to read to her when doing their homework because she was illiterate and relied on her daughters to help the grandchildren with their homework.

4.3.3.8 Support system

Mama Joyce mentioned that Cotlands was her most important support system. They had helped her to access the child care grants, provided the house she was living in, provided all the furniture in the home including the beds, previously provided groceries every month (but this had since stopped because Cotlands could no longer sustain this) and she could attend gogo support group meetings when she wanted to. Cotlands previously provided transport for gogos to attend support group meetings but could no longer sustain this service either. Cotlands have dedicated community health care workers who regularly visit grandmothers caring for orphaned grandchildren ensuring that their ARV treatment is adhered to. Mama Joyce also gave credit to her youngest daughter saying, “You know this one is like my husband. She helps me be strong.”

4.3.3.9 Resilience factors

The family agreed that without the support from Cotlands, they would have been in dire straits.

4.3.3.10 Talking about sex and HIV/AIDS

Despite the fact that AIDS has impacted this family so heavily, it is not spoken about openly. When referring to her nephew, the aunt said, "I think he knows his status." Sex is also a taboo subject. She also mentioned that she was very concerned about him (the fourteen year old nephew) because he seemed to be depressed. She said that he went for counselling but did not speak.

4.3.3.11 Experience of losing a parent

The grandchildren did not remember much of this period of their lives.

4.3.3.12 Positive aspects to being raised by a grandparent

The younger grandson said that he loved his Gogo. I was informed that he had previously said the following to his grandmother, "I don't want you to die now. You can die when I'm old." They basically could not remember their lives without their grandmother.

4.3.3.13 Challenges with regard to being raised by an elderly caregiver

The grandchildren could not respond to this question but the aunt, when referring to her seven year old nephew explained that he needed someone to take him out to play with other kids, to eat at Mc Donalds and he needed a mother's individualised care and attention.

4.3.3.14 Future goals

As a family they wanted to get more income so that life would be easier for them. The aunt's goal was to go to university to study hospitality and catering so that she could provide for the family when Mama Joyce passed on.

4.3.3.15 Suggestions for supporting agencies

They agreed that all the services that Cotlands was providing before their financial difficulties were what any supporting agency should do.

4.3.3.16 Synthesis and conclusion of interview: case study three

This interview illustrated the danger of creating dependence and then not being able to sustain the support to a family that was originally given by a supporting agency. Mama Joyce's family live in abject poverty and are solely reliant on income they receive from the government for the care of two children,

but which is also used to provide for the needs of four adults living in the home. The interview also highlighted the fact that grandparents' health needs need to be taken more seriously. A poignant aspect that was raised was that children require individualised care and attention which elderly caregivers are not often in a position to do. The emotional needs of orphans need to be taken very seriously. The support that other adults in the home sometimes offer to grandparents was also well illustrated in this interview.

4.4 SYNTHESIS AND INTERPRETATION OF THEMES

When reviewing the data from my empirical investigation of grandparent-headed households the following five themes emerged: *precipitating factors leading to the phenomenon of grandparent-headed households; stressors and challenges faced by grandparents and orphaned grandchildren; ongoing needs of grandparents and orphaned grandchildren; the resilience of grandparents and orphaned grandchildren and external support available to grandparent-headed households.*

From the interviews I conducted it appeared that the predominant factor leading to the phenomenon of grandchildren being cared for by their grandparents was the death of parents (the so-called middle generation) from AIDS related illnesses. Crothers (2001) as quoted in Smit (2007:166) confirms this fact by explaining that AIDS has brought about "household demographic structures hollowed out with only grandparents and children present." Monasch and Boerma (2004) as quoted in Ferreira (2007:11) state that in South Africa 60% of orphans due to AIDS live in a grandparent-headed household. A second factor was grandchildren being abandoned by their biological parents who simply left them in the care of the grandparents. I also came across instances where parents never assumed responsibility for their children and seemingly "disappeared" soon after the birth of their child. There was one example of a child whose parent died in a motor vehicle accident and the grandmother agreed to take care of him.

UNICEF (2010:1) suggests that the HIV/AIDS pandemic, together with floods, droughts, increasing food prices, armed conflict and economic recession have broken the spirit of many families in a large part of sub-Saharan Africa. This was borne out by the grandparents and grandchildren whom I interviewed who spoke of the pervasive challenges they faced on a daily basis.

A major stressor faced by most grandparents was physical health issues which included chronic illnesses such as hypertension, diabetes, arthritis, osteoporosis and cancer (particularly breast and cervical as mentioned by Vivienne and Althea from G.A.P.A.). These illnesses coincide slightly with those reported by Ferreira (2007:22) who also listed paralysis, poor balance, headaches and tiredness as common

illnesses suffered by elderly carers of grandchildren. Save the Children [UK] (2007:4) strengthen the claim that caring for HIV/AIDS orphans impacts on the health of grandparents. Grandparents are at a stage of their lives when they should be taken care of by younger relatives but due to the absence of the middle generation they have no option but to take on the demanding role of caring for young and often sick grandchildren and this is obviously taking its toll, both emotionally and physically, on elderly grandparents. Related to this issue is the frustration that many grandparents experience in firstly getting to community health clinics and secondly in having to wait there in endless queues often without the guarantee of receiving necessary medical attention and treatment. Family health International (2001:4) stress the fact that for the needs of orphans and other vulnerable children to be fully met, they and their guardians need to have access to appropriate health care including clinical and preventive health care services.

In my view there is a significant link between the grandparents' physical health issues and the emotional health issues they reported which included factors like stress (due to a number of challenges such as financial constraints, their inability to manage their grandchildren's behaviour etc.), feeling overwhelmed, Post Traumatic Stress Disorder (as mentioned by Vivien from G.A.P.A) as a result of even childhood trauma, chronic depression, feelings of hopelessness and immense grief as a result of losing their adult children. Grandparents' need for grief counselling cannot be emphasised enough, in my view. Ferreira (2007:22) also listed depression as a common issue for elders who raised grandchildren.

A third stressor faced by grandparents was that of financial exploitation by relatives as well as loan sharks and corrupt government officials. As Pastor Banzi mentioned, they were not successful in protecting grandmothers from this scourge. I believe that grandparents are vulnerable to exploitation because of their trusting natures but mainly due to their naivety linked to their low levels of education. See appendix 7 for a further example of exploitation of grandmothers by unscrupulous relatives (grandchildren).

Grandmothers without exception spoke about the stressor of insufficient income and living in poverty. This issue pervaded their entire existence. Andrews et al. (2006:273) state that households with orphans are more likely to be poor. The findings of my research seem to strengthen the argument put forward by UNICEF (2003:17) that poverty in homes occupied by orphans can be attributed to the increased dependency ratio meaning that the income of fewer adults earning a living is sustaining more dependants. I have come to the conclusion that if grandparents could simply have access to more money their burdens would be immeasurably lifted and grandchildren in turn would be shielded from so much

pain and misery. The grandparents themselves mentioned that they would get by on double the amount they were presently receiving from their state pensions.

A further stressor faced by grandparents (particularly in the Western Cape) was the fact that their grandchildren did not have birth certificates which meant that they were unable to access financial aid from the government which obviously increased the financial burden of caring for them. UNICEF (2003:43) states that children whose births are not registered are at risk of not having access to many of their rights. According to UNICEF (2003:43) this is a fairly common problem because in 2000 more than 66% of children's births in sub-Saharan Africa went unregistered. In South Africa, the Department of Home Affairs has justifiably received a significant amount of bad press regarding their lack of service delivery and my hypothesis is that this is impacting severely on the most vulnerable in society, especially on grandparent-headed households. Unfortunately some measure of blame also has to be directed toward the parents (middle generation) who neglected to register the births of their children.

Talking openly to grandchildren about sex and sexually transmitted illnesses like HIV/AIDS was a task that many grandparents found nearly impossible to do. This could be ascribed to the fact that it was regarded as a taboo subject in their own homes when they were growing up and they never had the opportunity to learn how to have these necessary conversations. I was heartened by the approach taken by goGogetters where grandmothers were practically trained (using role plays) in how to have these conversations with youth. I feel strongly about the necessity of bringing this subject of sex to the surface because the silence on the subject is literally killing millions of people in Africa and around the globe.

If Mama Joyce's experience of having to care for an orphaned grandchild with special needs is representative of many others in South Africa then this stressor would warrant special focus and attention by other researchers and hopefully by relevant government departments and non government organisations.

My research revealed a host of challenges and stressors faced by orphans in grandparent-headed households. The number of issues raised by young people during the interviews corroborated the statement by the 9-year old AIDS orphan (Giese 2002:15) that, "When a mother dies, children suffer." What struck me, whilst speaking to these young people, was the fact that the issues they raised were not given as complaints or as attempts at evoking sympathy, but simply as realities they faced on a daily basis.

Young people spoke of the stigmatisation and victimisation they were subjected to by peers because of their HIV status. It appeared that grandparents were not always able to shield their grandchildren from these psychological onslaughts which confirms the claim by UNAIDS (2004:9) that the most severe impact on these children was the loss of affection, support and protection. It was interesting, though, that grandchildren reported that they had hidden many of their problems from their grandparents in order to prevent loading their elderly caregivers with even more problems which in turn would exacerbate their poor state of physical and emotional health.

It was obvious that all of the orphaned young people really missed their parents (particularly their mothers) and longed to “hear her voice again”. Very few of them had received grief counselling after the death of their parents and in my view many of them displayed symptoms of depression. Antwine et al. (2005) in Avert [a] (2009:2) found high levels of psychological distress in AIDS orphans in rural Uganda and reported that anxiety, depression and anger were more common among AIDS orphans than other children.

The shortage of money was mentioned by every young person as a stressor. This supports the statement by Meursing (1997) in Mudavanhu (2008:24) that even after patients have died from AIDS, surviving family members experience severe hardship in trying to cope with the economic setback as a consequence of the illness. It was interesting to note that young people rarely mentioned that there was insufficient food at home but rather the lack of money prevented them from getting “nice things” as Pumlani mentioned.

Grandchildren complained about the fact that their grandmothers did not trust them with regard to their relationships with young people of the opposite sex. This, in my view, is probably due to grandparents’ concern about their grandchildren falling pregnant and/or becoming infected with HIV or other sexually transmitted infections but because of their inability to talk openly about sex they chose rather to convey their disapproval of these relationships.

The young people I spoke to were resigned to the fact that their grandmothers lacked the energy to support them in their school and extra-mural activities and were very much on their own in this regard. It was disappointing to note that schools had not been more sensitive to this fact and had not reached out to these families in any way to offer additional support and guidance.

A further stressor raised by young people in grandparent-headed homes was the fact that they were required to take on a number of adult roles in the home which impinged on their available time for

schoolwork and social activities. This supports the claim by Boler and Carroll (2003:5) that by taking on more responsibilities at home, orphaned and vulnerable children have less time for education. Boler and Carroll (2003:5) also state that education is regarded by caregivers of orphaned and vulnerable children as less important than domestic responsibilities. I found, though, that most grandparents valued their grandchildren's education and genuinely wanted them to be successful in this regard. Pumlani illustrated this when speaking of his grandmother said, "She makes it possible for me to be at school." Mama Sophie rued the fact that she was unable to afford tertiary education tuition fees for her granddaughter. My finding is supported by the United Nations Department of Economic and Social Affairs/Population Division report (2008:50) which stated that living with a grandparent is generally associated with higher educational enrolment for orphans than is living with other relatives, particularly more distant relatives.

A significant stressor for young people was their grandmothers' poor state of health which played on their minds to such an extent that they were unable to concentrate at school (as Gift explained). Linked to this was the real possibility of the death of their grandmothers and their concern about their own future once their grandmother passed away. I believe the grandchildren's concern for their grandmothers' well-being emanated from genuine empathy for their elderly caregiver but also out of concern about their own futures. Permanency planning for young people in grandparent-headed households is a very real need.

The third theme that emerged from my empirical research was the ongoing needs of grandparents and their orphaned grandchildren. Grandparents would be in a far better position to take care of orphaned grandchildren if their following needs were addressed by relevant government departments, non-government organisations, churches and helping professions:

Recognition has to be given to the fact that grandparents in these circumstances have lost their own children and are in desperate need of grief counselling and psychosocial support in general. Nompumelelo recognised this need when she said, "My grandmother doesn't understand why my mother passed away. She needs help with the grief of losing her daughter." Since their grandchildren were thrust upon them before and immediately after the death of their adult children (the middle generation), or the disappearance of their adult children in some cases, grandparents had no option but to continue with life and to put their own grief aside so that the needs of their orphaned grandchildren could be met. I realised that this was a need expressed by everyone around grandparents except by the grandparents themselves which implies that helping agencies should be proactive in providing these services and not rely on grandparents to seek them out for emotional support. Linked to this is the fact that many grandparents were unaware of resources that were available to them through non government

organisations operating in their township or townships in proximity to their own. This implies that helping agencies need to improve on their marketing strategies in informing their target client group of the services they offer.

Grandparent-headed households simply need more money. Grandparents are not managing to meet the physical needs of their grandchildren as well as their own because their expenses exceed their income. Related to the need for money is that many grandparents need assistance in navigating the bureaucratic system instituted by government departments to acquire decent housing, foster grants, disability grants, pensions et cetera. Grandparents also need to be taught how to be more effective and efficient with the money they do have and to be protected from exploitation.

Grandparents need help in raising grandchildren who have been socialised in a society which is very different from the one they grew up in. They need help in managing the behaviour of their grandchildren; in accessing scholastic support for their grandchildren; and in learning how to speak to their grandchildren about sex and boy-girl relationships in general.

Grandparents need practical help in keeping their homes clean, in getting to clinics and hospitals and in easier access to medical and palliative care.

Lastly grandparents have a need to feel valued, respected and heard. The stakeholder focus group came to the conclusion that personnel working directly with grandparent-headed households needed to understand the value of people and to be good listeners. Grandmothers represent the most disempowered group of people in South Africa having lived the majority of their lives during the apartheid era where they as young African girls were largely treated as commodities and regarded as cheap labour or as sexual objects. Althea, from G.A.P.A. had mentioned that many grandmothers in their programme suffered from Post Traumatic Stress Disorder as a result of rape and other trauma they had been subjected to during their childhood years.

Most of the orphaned grandchildren I interviewed were adolescents. Ruland et al. (2005:2) point out that the kinds of help that adolescent orphans need differ from that needed by children. The needs (of orphaned grandchildren) expressed by the adolescents themselves or identified by their grandmothers as well as by stakeholders included:

- Emotional support and counselling addressing psychological pain rooted in grief, loss, depression, victimisation and stigmatisation. This confirms the point raised by Children on the

Brink (2004) in Ruland et al. (2005:5) that losing a parent intensifies the emotions of anger, resentment, hopelessness and depression and in turn can lead to a sense of alienation, desperation and withdrawal and ultimately to vulnerability to HIV;

- role models who would mentor and motivate these young people through the tumultuous years of adolescence. This need was confirmed by Ruland et al. (2005:2);
- tutors to offer educational support in the light of the grandparents' low levels of education. Boler and Carroll (2003:5) also identified this as a need and suggested mentor schemes for emotional and intellectual support;
- permanency planning. Many of the young people spoke of their anxiety about their living arrangements after the death of their grandparents. This, for example, was an issue raised by Gift who mentioned that his grandmother was also stressed about what would happen to him after her death. Mama Joyce's younger grandson shared this concern when he had reportedly said to his grandmother that she could die when he was old;
- finances to ensure that they could continue with their education and to enable them to lead normal adolescent lives. Mama Sophie's granddaughters, for instance, mentioned that they were tired of sitting around and their biggest desire was to study further in order to get good jobs and earn decent salaries. Siyanda and Pumlani had set their sights reasonably high in wanting to become a pharmacist and pilot respectively but neither of these dreams would materialise in the absence of bursaries or study loans. Children on the Brink (2004) in Ruland et al. (2005:5) suggest that struggling to cope financially deprives many adolescents of much needed recreation and participation in community activities which in turn made them vulnerable to depression, hopelessness and risky behaviour;
- the burden of caring for their elderly caregivers to be lifted from them. This need was noted by Ruland et al. (2005:5) who claim that orphaned adolescents often have more challenges which include becoming household caretakers or breadwinners. Mama Sophie had mentioned that her grandchildren were "looking after me now" and Nompumelelo verbalised her need for an agency to take care of her grandmother's needs so that the burden of caring for her could be lifted and she could pursue her own dreams and enjoy peace of mind knowing her grandmother was being cared for.

When reviewing this list of needs one is astounded by the large void that remains in families when the middle generation is snuffed out by AIDS and the severe impact it makes on those left behind in the wake of their deaths.

The fourth theme that emerged from my empirical research was the resilience shown by grandparents and orphaned grandchildren in grandparent-headed households. Resilience is described by Walsh (1998) in Brendtro and du Toit (2005:40) as the ability to rebound from adversity with greater strength to meet future challenges.

Stephen Lewis, the former UN Special Envoy for HIV/AIDS in Africa, described African grandmothers as the “unsung heroes of the continent: these extraordinary, resilient, courageous women...” (Ferreira 2007:17). The grandmothers’ resilience was demonstrated through:

- Their willingness to take on the massive responsibility of caring for orphaned grandchildren at a stage of their lives where they were supposed to be “enjoying a hard-earned rest” (Nini 2010:3). Mama Sophie in Khayelitsha, for instance, explained that it was “just normal” that she would take care of her grandchildren when their mothers passed away because “their mothers are my daughters, my blood.”
- their generosity in taking in children who were not even directly related to them;
- the entrepreneurial spirit displayed by some grandmothers who found ways to supplement their income through selling sweets and juice and to source educational support for their grandchildren by requesting help from older youth in the community or through borrowing money from neighbours to ensure that their families did not go without food;
- supporting each other as Mama Florence had done when initiating a support group for grandmothers in her neighbourhood;
- their willingness to be actively involved in community programmes like goGogetters (where they championed the cause of vulnerable young people in the community who were not even related to them while still having to take care of their own orphaned grandchildren) or the GoGo Trust (where they facilitated soup cells for other grandmothers);
- the many sacrifices they made in ensuring that their grandchildren’s needs were met. A few grandchildren whom I interviewed, for example, had noticed how their grandmothers had desisted buying clothes for themselves so that the grandchildren could get what they needed;
- their faith in God to provide for their physical needs (which, according to them, was regularly rewarded through supernatural provision) . Mama Sophie, for example, had mentioned that, “God is making our stomachs full.”

Garmezzy (1983) in Brendtro and du Toit (2005:41) stated that, “If there is any lesson to be derived from recent studies, it lies in the reaffirmation of the resilience potential that exists in children under stress.”

This was certainly the case in the young people whom I interviewed who demonstrated their resilience through:

- Their show of appreciation for what their grandmothers had done for them despite their difficult circumstances ;
- their acts of kindness toward their frail grandmothers and their genuine empathy for them with regard to their health issues;
- having aspirations of being successful despite their current situations and regarding their future success as a payback to their grandmothers rather than for their own selfish gain;
- their contentment with and absence from bemoaning their poor living conditions;
- their attempts to shield their grandmothers from further misery by withholding some of their own issues from their grandmothers;
- their grit and determination to survive after the death of their grandmothers;
- their willingness to give up their own enjoyment and social lives and making attempts to bring in supplementary income (as Zanoxolo had done) for the benefit of their families;
- their scholastic success in the face of arduous circumstances as illustrated by Nompumelelo who passed grade twelve in the same year that her mother became desperately ill and subsequently passed away and
- devising their own strategies to deal with psychological pain in the absence of professional psychosocial support.

The fifth theme was that of external supports available to grandparent-headed households. Brendtro and du Toit (2005: 41) state that resilience does not only involve inner strength of a person but also support from those in the environment. My empirical research showed that despite the fact that so much more needs to be done to support grandparent-headed households, there are, nonetheless, a number of external supports available to them. These include:

- Extended family. Mama Anthea, for example, mentioned that her daughter-in-law sometimes visited her to check up on her well-being and often brought food for the family and Phumulo who spoke of his maternal aunt who had spoken to him about his late mother;
- churches. Pastor Banzi has instituted the “Kingdom Women in Leadership” programme as one of the ministries of his church to reach orphans and grandparents in the Motherwell community;

- community members and neighbours. The spirit of ubuntu appears to still be a value in the townships of South Africa where neighbours generously share food and lend money to struggling families like Mama Sophie's family in Khayelitsha;
- non government organisations like the GoGo Trust, Sisonke Sophumulelo, goGogetters, G.A.P.A., and Cotlands who offer very valuable support to grandparent-headed households and;
- government departments like the Department of Social Development which provides grants and pensions to the members of these households. Pumlani mentioned that a social worker from this department gave him emotional support after his mother died.

The interviews with the two families in Cape Town and Johannesburg respectively and with the focus group participants in Port Elizabeth showed that most of the issues raised could be common to grandparent-headed households throughout South Africa. The hardships described by both families can be directly attributed to HIV/AIDS. Both situations illustrate the fact that if something seriously is not done to stop the spread of the virus, the cycle of poverty will continue for many years to come in South Africa. Grandparents are made to take on responsibilities which are beyond their means and capabilities.

4.5 CONCLUSION

Chapter four has aimed to present, analyse and interpret the empirical research findings.

Chapter five, which follows, contains a summarising presentation of significant findings. Recommendations and guidelines for agencies setting out to offer support to grandparent-headed households will be followed by suggestions for future research.

CHAPTER 5: OVERVIEW OF THE STUDY AND RECOMMENDATIONS

5.1 INTRODUCTION

Chapter four provided a detailed analysis and interpretation of the results of the empirical research that was undertaken. Chapter five aims to supply an inclusive overview of the entire study. This chapter will also include suggestions for future areas of study and recommendations and guidelines are proposed for use by agencies setting out to provide support services to grandparent-headed households.

The aim of this research was to find answers to the following:

What guidelines are necessary for empowering grandparents who fulfil the role of parents in the context of the HIV/AIDS pandemic?

5.2 OVERVIEW OF THE INVESTIGATION

In order to address the afore-mentioned research problem, an extensive literature study was conducted to investigate various aspects regarding grandparent-headed households. A range of topics including the following were explored:

- Prevalence of HIV/AIDS: globally, in Africa and in South Africa.
- Prevalence of grandparent-headed households.
- Physical, educational and psychosocial needs of orphaned children.
- Erik Erikson's ego psychological theory
- The needs of adolescent orphans.
- Characteristics of grandparent-headed households.
- Prevalence of organisations lending support to grandparent-headed households

For the purposes of the empirical investigation that was carried out I made use of qualitative research methodology and applied the following methods:

- Focus groups
- Case studies

5.3 OVERALL SUMMARY AND SYNTHESIS OF FINDINGS

I have attempted in this section to integrate the important findings of the literature study and the empirical findings simultaneously.

5.3.1 Prevalence of HIV/AIDS

According to Avert[a] (2009:1) [refer to 2.2.1] it is estimated that more than 15 million children younger than 18 years around the world have been orphaned because of AIDS. Dawes et al. (2007:359) [refer to 2.2.2] reported that 64% of the world's population living with AIDS live in sub-Saharan Africa despite the fact that the sub-continent made up only 10% of the world's population. Avert[b] (2009:1) [refer to 2.2.2] indicate that more than 14 million children in sub-Saharan Africa have lost one or both parents to AIDS since the epidemic began. A shocking statistic given by AIDS Foundation South Africa (2009:3) [refer to 2.2.3] is that in 2008 South Africa had the highest number of people infected worldwide, estimated at approximately 5,3 million, including 220 000 children younger than 15 years. The ASSA2003 AIDS and Demographic model (Nicolay 2008:4) [refer to 2.2.3] shows that an estimated 11% of the population in the Eastern Cape were HIV positive in 2008.

5.3.2 The *grandmothers' disease*

SASIX (2010:1) [refer to 2.3] referred to AIDS in South Africa as the *grandmothers' disease* because grandmothers have no other option but to take on the full responsibility of raising and supporting their grandchildren whose parents have died of AIDS. This was borne out by the grandparents in the grandmothers caring for orphaned grandchildren focus group (refer to 4.2.1.2) as well as by the two family case studies (refer to 4.3.2.1 and 4.3.3.2) who stated that circumstances dictated that they would take over the care of their grandchildren. There were simply no alternatives.

5.3.3 Grief of grandmothers and orphans

Stephen Lewis as quoted in Ferreira (2007:17) [refer to 2.3] referred to the inconsolable grief of grandmothers at the loss of their adult children. The stakeholders mentioned this in their focus group (refer to 4.2.2.4) describing the immense grief of grandmothers and orphans as one of their biggest challenges. One of the orphans in the focus group (refer to 4.2.3.10) also

recognised this fact. Lewis also spoke of the “nightmare” which grandparents experienced at not knowing what would happen to their grandchildren when they died (refer to 2.3). During the focus group an orphan reported that his grandmother was stressed about what would happen to him after her death (refer to 4.2.3.10).

5.3.4 Sources of income

Barnett and Blaikie (1992) are quoted in Dayton and Ainsworth (2002:3) [refer to 2.3] mentioning that the elderly sometimes found themselves in households where there are no economically active adults. This applied to all the participants in the grandmother focus group whose only source of income was their state pensions (refer to 4.2.1.5) as well as to both case study families (refer to 4.3.2.3 and 4.3.3.4) where in one case the grandmother did not receive a pension but relied on income in the form of two child support grants for her grandchildren.

5.3.5 Orphans cared for by women

UNICEF (2003:16) [refer to 2.3] revealed that households headed by women more often took responsibility for orphans. All the participants in the orphans focus group stated that they were cared for by their elderly grandmothers (refer to 4.2.3.1). One grandmother still had a life partner but he was seriously ill and was also dependent on his wife. During my interview with the case study family in Khayelitsha, one of the adolescent granddaughters estimated that approximately 60% of families in their immediate neighbourhood were headed by elderly grandmothers because the children’s parents had presumably died from AIDS. This estimate is in line with a statistic given by Monasch and Boerma (2004) in Ferreira (2007:11) [refer to 2.3] who stated that 60% of AIDS orphans in South Africa lived in grandparent-headed households.

5.3.6 Challenges after AIDS deaths

Meursing (1997) is quoted in Mudavanhu (2008:24) [refer to 2.4.1] explaining that surviving family members experience serious hardship after the death of patients from AIDS in trying to cope with the financial setback as a consequence of the illness. This applied to all the orphans in the focus group (refer to 4.2.3.2) and the grandmothers in the first focus group (refer to 4.2.1.7) as well as to both case study families (refer to 4.3.2.6 and 4.3.3.4)

5.3.7 Access to medication

Delegates at an interactive conference in Cameroon in 2004 organised by the Commission on HIV/AIDS and Governance in Africa [CHGA] (2004:17) stated that orphans often do not have access to medication, particularly anti-retroviral therapy. This does not appear to apply in South Africa. My empirical research revealed that a family connected to a supporting agency in Johannesburg even had a community health care worker regularly visiting their home to monitor their adherence to the anti-retroviral therapy (refer to 4.3.3.8).

5.3.8 Anxiety and its influence on learning

Boler and Carroll (2003:1) [refer to 2.4.2] mention the fact that orphans may be enrolled at school but may not be learning because they may be anxious about loved ones at home. One of the participants in the orphan focus group made this very point (refer to 4.2.3.8) when stating that he sometimes could not concentrate at school because he was so concerned about his grandmother's health.

5.3.9 Grandparent-headed households and educational disadvantage

The United Nations Department of Economic and Social Affairs/Population Division report on the Impact of AIDS on Households (2008:50) [refer to 2.4.2] suggests that even though grandparent-headed households tend to be female-headed and poor, living with a grandparent is generally associated with higher educational enrolment for orphans compared to those living with other relatives. All the orphans in the focus group were attending school or had completed their schooling (refer to 4.2.3.1). What I did find was that those who had completed their schooling were not able to access tertiary education (which they referred to as 'school') because of poverty (refer to 4.3.2.13 and 4.3.3.14)

Boler and Carroll (2003:5-6) [refer to 2.4.2] list characteristics of orphaned and vulnerable children which can cause educational disadvantage. One characteristic mentioned is that of stigma. The participants in the grandmother focus group raised this as an issue and suggested that their grandchildren needed counselling in this regard (refer to 4.2.1.12). Another characteristic listed was lack of homework support. Despite the fact that grandmothers in the focus group were not educated sufficiently to be of much help to their grandchildren with regard to their homework, they all tried to "make a plan" by requesting

young people in the neighbourhood to help their grandchildren with their homework (refer to 4.2.1.8).

5.3.10 Support groups for grieving children

Wells (1993) in Reyneke-Barnard (2006:53) [refer to 2.4.3] provides a number of practical guidelines for helping children who grieve. One such suggestion is giving them access to support groups. None of the participants in the orphan focus group nor any of the children in the family case studies had had an opportunity to attend a support group (refer to 4.2.3.4). The *Sisonke Sophumulela* programme, however, referred to in 4.2.2.1 did offer weekly support groups.

5.3.11 Orphaned adolescents and recreation

Ruland et al. (2005:5) [refer to 2.4.4] discuss the fact that orphaned adolescents often have more challenges including becoming household caretakers. This was certainly the experience of Nompumelelo in the orphan focus group (refer to 4.2.3.11) who dreamt of having an agency relieving her of her caretaking responsibilities.

According to Children on the Brink (2004) in Ruland et al. (2005:5) [refer to 2.4.4] many adolescents are deprived of much needed recreation because of struggling to cope financially. Zanoxolo from the orphan focus group, for instance, spent his weekends and holidays doing odd-jobs to supplement the family income (refer to 4.2.3.7) Phumulo, on the other hand, pursued his passion for soccer but felt badly about not doing enough for his grandmother (refer to 4.2.3.8)

5.3.12 Emotions experienced by orphaned adolescents

Berger et al. as quoted in Laverne (2007:2) [refer to 2.4.4] state that since the adolescent is trying to find his identity and that the parent is a role modelling figure who is able to help with guiding and encouraging this process, it is not surprising that an adolescent orphan feels helpless, dependent and even angry. Some of this anger manifested during the orphan group when young people expressed their frustration at not having parents that they could turn to (refer to 4.2.3.6).

5.3.13 Understanding of death

In Laverne (2007:3) Kalish (1977) is quoted explaining that in modernised society, a parent is blamed for creating internal processes that led to their own death (for example smoking, poor eating habits, unprotected sex et cetera). In other cultures the death is attributed to external agents like evil spirits or magic. In the orphan focus group Nompumelelo said that her gogo needed counselling because she could not understand why her daughter had passed away (refer to 4.2.3.10). The grandparents in my two case studies were very clear about the fact that their daughters had died from AIDS and both understood how the HI virus was transmitted (refer to 4.3.2.1 and 4.3.3.1).

5.3.14 Dependence on government support

According to the Australian Bureau of Statistics' 2003 Family Characteristics Survey as quoted in Mission Australia (2007:1) [refer to 2.5.2] approximately two-thirds of the grandparents who cared permanently for their orphaned grandchildren in the survey were dependent on government pension, benefit or allowance as their main source of income. The empirical research indicated that in South Africa this figure would be closer to one hundred percent (refer to 4.2.1.5; 4.3.2.3 and 4.3.3.4)

5.3.15 Grandparents as guardians to orphans of more than one adult child

Floyd et al. (2007:789) [refer to 2.5.3] refer to the fact that grandparents may be the guardians to grandchildren from more than one son or daughter. Mama Florence in the grandmother focus group for example informed the group that both her daughters had died and she was the guardian to their daughters (refer to 4.2.1.2). Mama Sophie in my case study family also had the responsibility of caring for her late daughters' children and in fact had great grandchildren to take care of also (refer to 4.3.2.1).

5.3.16 Grandparents borrowing money

UNICEF (2003:19) [refer to 2.5.3] reveal the findings of a United Nations Food and Agricultural Organisation study in Uganda where it was found that amongst other methods, widows were borrowing money from extended family and friends to make ends meet. A granddaughter in Mama Sophie's family (refer to 4.3.2.3) revealed that they were always

borrowing money and paying it back. While doing my empirical research I discovered the phenomenon of *Skoppers who* exploited poor grandmothers by lending them money at highly inflated interest rates (refer to 4.2.1.7).

5.3.17 Gender of orphans in grandparent-headed households

Evans (2005:10) [refer to 2.5.3] reports that boy orphans are more likely than girl orphans to stay with grandparents. My empirical research did not set out to test this fact but it so happened that in the grandmother focus group five of the grandmothers were caring for grandsons while Mama Florence was caring for two granddaughters (refer to 4.2.1.2). Evans argues that grandparents are more prepared to make short-term sacrifices for the longer term well-being of their grandchildren. This was certainly the perception of the participants in the orphan focus group who spoke of their grandmothers making personal sacrifices like not buying clothes for themselves so that the grandchildren would not have to go without (refer to 4.2.3.9).

5.3.18 Fathers of orphans

Zimmer and Dayton (2003:24) [refer to 2.5.3] show that in 15 countries of sub-Saharan Africa 1,7% of older adults live with at least one double-orphaned grandchild. What I found in the empirical research was that in most cases the fathers were simply absent and played no significant role in their children's lives. Many had no idea if their father was alive or not (refer to 4.2.3.1). This, in my view, would be an area of further investigation, finding out why fathers are not assuming responsibility for their offspring.

5.3.19 Education levels of grandparents

Evans (2005:10) [refer to 2.5.3] shows that orphans in sub-Saharan Africa are likely to go to households where the household head has on average 0,5 years less schooling and explains that this may be because large proportion of orphans live with grandparents who on average have less education. My empirical research corroborated this fact. In the focus group for grandparents, two grannies had had no education, three had completed six years of schooling or less and one had successfully completed ten years of schooling (refer to 4.2.1.1). Mama Sophie in my family case study had completed eight years of schooling (refer to 4.3.2.1) while Mama Joyce had completed only four years of schooling (refer to 4.3.3.1).

5.3.20 Orphans and birth registration

UNICEF (2003:43) [refer to 2.5.3] claims that children whose births are not registered are at risk of not having access to many of their rights including care giving support from the government. My empirical research showed that this not appear to be an issue for most of my subjects because most grandparents were receiving child care grants for their grandchildren who fell within the age-range prescribed by the government (refer to 4.2.1.5). Althea, from G.A.P.A., however, mentioned that in their experience many grandchildren of grandmothers in their programme did not have birth certificates which prevented them from applying for a government grant (refer to 4.3.1.4).

5.3.21 Grandparents and self-rated health status

Save the Children [UK] (2007:4) [refer to 2.5.3] highlight a number of common issues for carers of HIV/AIDS orphans and one of those mentioned is the lack of space in the home. This was certainly an issue for the two families interviewed in my case studies. Mama Joyce, for example, lived in a converted container with an area of twelve squared metres which is shared between six people and sometimes eight (refer to 4.3.3.3). Phumulo in the orphans focus group shared a one-room shack with his grandmother and a curtain is the only thing that gives both occupants a measure of privacy (refer to 4.2.3.2)

Ferreira (2007:22) [refer to 2.5.3] found that self-rated poor health reduces elders' involvement in responsibility for grandchildren but that elders continue to care for grandchildren in spite of physical limitations. Without exception every grandparent interviewed reported that they suffered from an ailment ranging from hypertension to diabetes and all experienced physical pain on a daily basis (refer to 4.2.1.3; 4.3.2.4 and 4.3.3.5)

5.3.22 Support agencies

With regard to organisations lending support to grandparent-headed households my experience was that there do appear to be such organisations in each major city of South Africa but the startling aspect for me was that they did not know about each other's existence and therefore did not network with each other. For example, in the stakeholders focus group,

this was the first time these organisations had sat around the same table even though they were doing similar work (refer to 4.2.2.1)

5.4 RECOMMENDATIONS

Based on the foregoing findings from the literature study and the data collected as part of the empirical investigation, the following recommendations are proposed in order to assist schools, non-government organisations, government and helping professionals who endeavour to empower grandparents in their role as parents to their orphaned grandchildren in the context of the HIV/AIDS pandemic:

5.4.1 Recommendations for schools

- Establish a programme which assists grandchildren with education support after school in the form of volunteer tutors;
- enrol grandparents in adult literacy and numeracy classes;
- help grandparents to get their pre-school grandchildren into playschools and pre-schools to relieve them of some of their care giving responsibilities but also to ensure that the children receive adequate early childhood educare;
- conduct surveys in the school to determine who the orphans are and then establish a support group for them in the school;
- provide a feeding scheme for orphans from grandparent-headed households in the school;
- encourage teachers to visit the homes of their learners to gain some understanding of their circumstances;
- provide career guidance for these learners;
- exempt orphans from having to pay school fees and
- link them to bursary schemes for tertiary education.

5.4.2 Recommendations for non-government organisations

- Establish relationships with government department heads who can facilitate easy access to government services like applying for birth certificates and child care grants et cetera;

- establish support groups for grandparents who share common challenges. They desperately need to have a forum where they are free to express their emotions and to receive psychosocial support and also to have fun;
- always keep your commitments to grandmothers so that their trust in you is established;
- help the grandparent support groups to establish their own 'banks' where funds are lent to members of the group at a small interest but where the capital amount remains within the group rather than with exploitative loan sharks;
- identify grandmothers who can become leaders over other grandmothers and train them in facilitation skills, communication, financial management and in counselling skills;
- provide an outlet for grandmothers' strong sense of spirituality;
- teach grandparents how to budget and to spend money wisely. Grandparents are teachable. They need to learn skills that could ultimately be a source of income to their families. For example, they can learn to sew, knit, crochet, make food gardens et cetera. They need to learn about managing children's behaviour without resorting to physical punishment. Grandparents need to learn how to broach the subject of sex with grandchildren and learn to become more comfortable in doing so. Remember that grandmothers do not respond well to lectures but feel energised and empowered when participating in role plays. Do not create dependence in grandparent-headed households but try to empower these families to become more self-sufficient;
- recognise grandparents as key players in the fight against AIDS. The goGogetter model is an excellent one, in my view, where grannies are used as mentors to youth in the community and not just to their own grandchildren;
- establish peer support groups and programmes for grandchildren in these grandparent-headed families similar to those offered by *Sisonke Sophumelela* where youth workers visit them in their homes, have accompanied food shopping opportunities, provide them with resources like fuel for cooking so that they experience the joy of contributing to their homes, receive counselling to address their grief at losing their parents and are referred to specialist services;
- network with other organisations doing similar work and start tapping into resources that are available;

- find out about conferences that focus on the needs of grandparents and have grandparents and agency staff attend these conferences;
- try to access part-time employment for older grandchildren so that they are able to be contributors to the family's income;

5.4.3 Recommendations for government

- Take the grandmothers' health needs seriously and utilise the services of trained medical professionals to regularly monitor the grandmothers' health. The same personnel can be deployed to ensure that anti-retrovirals to HIV positive grandchildren are being administered correctly;
- help grandmothers with permanency planning for their grandchildren. This will relieve them of much stress as it is a factor that is constantly on their minds;
- investigate the real costs of caring for grandchildren and increase the financial allocations to grandparent-headed households;
- help these families to obtain the necessary legal documents like birth certificates;
- relieve children of the burden of being their grandparents' caregivers by providing the necessary services to these families;
- collaborate with non-government organisations providing services to grandparent-headed households and;
- attempt to locate grandchildren's fathers so that they can become an additional level to these families' support systems.

5.4.4 Recommendations for helping professions

- Do not forget that grandmothers have lost their adult children and are in dire need of grief counselling;
- identify signs of depression in grandmothers and provide the necessary therapeutic intervention;
- provide opportunities for young people to express their feelings of loss;
- make allowances for regressive behaviour in youth and offer comfort;
- expect and accept mood swings;
- examine one's own attitudes toward death so that one can fully understand the needs of the child going through the grieving process;

- do not unduly influence young people with regard to your personal religious beliefs at a time of grief and loss;
- be sensitive to the stage of loss that a grandparent or grandchild may be going through namely shock and denial, anger, bargaining, depression or acceptance;
- remember that adolescents often get comfort by sharing their pain with peers. Provide opportunities through group therapy for this to take place;
- be mindful of the fact that people grieve in different ways: some prefer to talk about the death; others may cry when they think about the person they have lost; some express their grief in creative ways through the arts while others prefer physical activities such as sports. Make provision for these;
- keep in mind that grieving children need to accept the reality of the loss; experience the pain or emotional aspects of the loss; adjust to a new reality in which the significant other is missed and find ways to remember the person;
- ensure that the following immediate needs of children after losing their parent are met; having their emotions validated; being given accurate information and being reassured about the future and;
- consider the use of journalling, relevant films and books on the subject of death and grieving with young people who have lost parents.

5.5 SUGGESTIONS FOR FUTURE RESEARCH

During the empirical study a number of questions not stipulated as part of this study emerged and they offer an opportunity for future research:

- A qualitative study of the phenomenon of grandparent-headed households in each major city;
- A qualitative study of support agencies providing care and support to grandparent-headed households in South Africa.
- Researching the role of grandmothers as mentors to youth.
- A study of the impact of absent fathers in the lives of orphaned grandchildren.
- A study of the effectiveness of the present government financing policies with regard to grandparent-headed households.
- A study of the impact on scholars of having poorly educated caregivers.
- The impact of poor living conditions on the education of orphans.

5.6 LIMITATIONS OF THE STUDY

This research study was limited in that it involved only a small sample of grandparent-headed households in three cities in South Africa. The study focused on grandparents living in township situations and those from indigenous cultures. The fact that the study did not include a quantitative investigation of the phenomenon of child-headed households was also a limitation. Due to this being a qualitative study implies that the interpretive process was limited to my personal cognition, opinion and bias. These factors obviously reduced the ability to generalise the research findings.

5.7 CONCLUSION

The aim of the study was to establish guidelines necessary for empowering grandparents who fulfil the role of parents in the context of the HIV/AIDS pandemic. The empirical investigation revealed the tremendous hardships that grandparents and orphans are living under and their absolute resilience and will to keep going despite these hardships. The study highlighted the need to empower grandparents and to equip them to fulfil a vital role in society that ideally should be fulfilled by parents. Government departments seriously need to focus on the needs of this vulnerable group of people and to respond to their needs appropriately.

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APPENDICES

APPENDIX 1: INFORMED CONSENT FORM

Research title: **Guidelines for empowering grandparents who fulfil the role as parents in the context of the HIV/AIDS pandemic**

Researcher's name: Cecil Wood

Reference number: 0691 340 7

Researcher's position: Master's student

Department: Education (Guidance & Counselling)

Address: P.O. Box 392 UNISA 0003

Contact telephone no.: 041 5816529; 083 652 7486

IMPORTANT MESSAGE TO PARTICIPANT

Dear Participant

Thank you for participating in this study. Should you, at any point during the study, experience an emergency as a result of the study or require any further information regarding the study, feel free to contact me at either of the numbers listed above.

Individual interviews will be conducted with you and will be tape-recorded, photographs will also be taken with your permission. The recording will be treated confidentially and will only be accessible to the researcher. If you insist on your name being published, only then will the researcher do so.

You are encouraged to answer questions but you do not need to answer particular questions if you do not wish to and can withdraw at any time from the interview. The researcher will ensure that all the material remains confidential and is stored safely. The final report of the study will be made available to those participants who wish to read it.

This is to confirm that I (name) consent to participate in the study. I understand that I can withdraw from the study at any time and that identification in the study will be my own decision.

Signature of participant :

Signature of researcher:

Date :

Thank you for participating in this study

APPENDIX 2: INFORMED CONSENT FORM

Research title: **Guidelines for empowering grandparents who fulfil the role as parents in the context of the HIV/AIDS pandemic**

Researcher's name: Cecil Wood

Reference number: 0691 340 7

Researcher's position: Master's student

Department: Education (Guidance & Counselling)

Address: P.O. Box 392 UNISA 0003

Contact telephone no.: 041 5816529; 083 652 7486

IMPORTANT MESSAGE TO PARTICIPANT

Dear Grandparent

Thank you for allowing your grandchild to participate in this study. Should you, at any point during the study, experience an emergency as a result of the study or require any further information regarding the study, feel free to contact me at either of the numbers listed above.

Your grandchild will be a participant in a focus group where the session will be tape-recorded. The recording will be treated confidentially and will only be accessible to the researcher.

Your grandchild is encouraged to answer questions but he or she does not need to answer particular questions if they do not wish to and can withdraw at any time from the interview. The researcher will ensure that all the material remains confidential and is stored safely. The final report of the study will be made available to those participants who wish to read it.

This is to confirm that I (name) grant consent for my grandchild to participate in the study. I understand that he/she can withdraw from the study at any time and that identification in the study will be my decision.

Signature of grandparent:

Signature of researcher:

Date:

Thank you for allowing your grandchild to participate in this study.

Appendix 3

Discussion guide: Grandmother focus group

1. Introduction

- Introduce myself
- Purpose of the Focus Group
- Focus group guidelines - no right/wrong answers as all opinions are valuable
 - speak one at a time so that voices will be clear on the recording
- Permission to audio record proceedings
- Approximate duration of focus group (2 hrs)
- Collect signed consent forms

2. Introduction of group members

Probe:

- Age
- Married/never married/widow
- Education level
- Number of orphans in their household
- Number of people in their homes
- Description of living conditions – access to water, sanitation, electricity etc.

3. Circumstances leading up to becoming parents to grandchildren

Probe:

- Nature of circumstances.
- How decision was made?
- Why them?

- Feelings around this issue?

4. Health of caregivers

Probe:

- Physical health issues
- Access to medical care
- Emotional health
- Emotional/psychological support

5. Financial aspects

Probe:

- Average monthly income
- Source(s) of income
- Average monthly costs
- How shortfall is dealt with

6. Difficulties

Probe:

- What is most difficult?
- Other challenges
- Coping mechanisms

7. Support

Probe:

- Awareness of agencies offering support
- What is most helpful?
- Community/social support
- Support systems in place

8. Needs

Probe:

- Most urgent needs
- Nature of needs – elaborate
- Wish list (apart from money)

9. Survival strategies

Probe:

- Financial aspects
- Generation gap
- Physical demands
- Emotional demands

10. Knowledge/Awareness regarding HIV/AIDS

Probe:

- Basic knowledge of HI virus
- Attitude toward sex
- Talking about sex
- Knowledge around prevention

11. Recommendations

Probe:

- Advice to agencies wanting to support grandparents in their situation
- Do's
- Don'ts

APPENDIX 4

Discussion Guide: Stakeholder focus group

1. Introduction

- Introduce myself
- Purpose of the Focus Group
- Focus group guidelines - no right/wrong answers as all opinions are valuable

- speak one at a time so that voices will be clear on the recording

- Permission to audio record proceedings
- Approximate duration of focus group (2 hrs)
- Collect signed consent forms

2. Introduction of group members

Probe:

- Own life circumstances
- Professional background

3. Involvement with grandparent-headed households

Probe:

- Present involvement
- Services offered
- Nature of involvement
- Origins of organisations represented

4. Profile of typical grandparent caring for orphaned grandchildren

Probe:

- Age spectrum
- Social circumstances
- Marital status
- No. of orphans being cared for
- Education levels
- Health
- Financial

5. Access by grandparents to services offered

Probe:

- Marketing strategies
- Outreach programmes
- Walk-ins / referrals
- Geographical position of organisation in relation to client group
- Criteria

6. Needs of grandparents

Probe:

- Needs their organisations are able to provide for.
- Needs their organisations are not able to meet.

7. Needs of orphaned grandchildren

Probe:

- Needs their organisations are able to provide for.
- Needs their organisations are not able to meet.

8. Supporting grandparent-headed households

Probe:

- What training is required & what qualities are necessary to do this work effectively?
- Funding
- Lessons learnt
- Guidelines
- What support does each organisation need?
- Networking with other agencies.

Appendix 5

Discussion Guide: Orphans focus group

1. Introduction

- Introduce myself
- Purpose of the Focus Group
- Focus group guidelines - no right/wrong answers as all opinions are valuable
 - speak one at a time so that voices will be clear on the recording
- Inform participants of audio recording
- Approximate duration of focus group (2 hrs)
- Collect signed consent forms (signed by grandparents)

2. Introduction of group members

Probe:

- Demographics: age, school grade, siblings, birth certificate, ID document
- Living conditions

3. Care Givers

Probe:

- Who takes care of them?
- How is it that they are being cared for by ↑?
- How long have they been with them?

4. Becoming orphans

Probe:

- Single/double orphans

- Awareness of facts around parents' passing
- Emotional support/counselling received at time of parents' passing
- What they miss most about their parents

5. Experience of being cared for by elderly caregiver(s)

Probe:

- What they appreciate most about their grandparent
- What specifically does grandparent(s) do for them
- What they would like their gogo to do better in meeting their needs
- The hardest thing about being raised by an elderly caregiver
- Their needs
- Educational support

6. Support for Grandparent(s)

Probe:

- The nature of the support they offer to their grandparent(s)
- What they could do more

7. Insight into grandparents' struggles

Probe:

- What they are concerned about w.r.t. their grandparents' well-being.
- Their perspective on the help/support their grandparents need from supporting agencies

8. Their future plans

Probe:

- If/when grandparents pass on
- Career plan

Appendix 6

A. Illustration of content analysis done with data from Grandparent focus group

Initial Coding:

- Abandonment by biological mother
- No option in caring for grandchild
- Also caring for late sibling's children
- More than one adult child died – taking care of orphans from two families
- Common illnesses among grandparents
- Monthly visits to clinic
- Emotionally stressed due to financial constraints
- Behavioural problems of grandchildren – inability to manage their behaviour
- Sources of income – not enough
- Abuse by loan sharks
- Poorly educated
- Use of resources in community
- Poor health a major concern
- Concern about dying before grandchild's future is secure
- Ways of broaching subject of sex with grandchildren
- Consequences of unprotected sex
- Drug abuse/rebellion
- Psychosocial support for grandparents
- Generosity/ubuntu of grandmother
- Teaching of skills to grandmothers
- Dearth of support to grandmothers
- Support of neighbours
- Pressing needs for : food, school uniforms, school fees, stationery, sports equipment, educational support for grandchildren, decent housing, behaviour management skills
- Orphans needing counselling – stigmatisation, victimisation, grief counselling
- Support group for Gogos
- Spirituality – faith in God sustained them

Recoding:

- Abandonment by biological parent
- Circumstances under which grandparents took on guardianship
- Orphans from more than one family in same grandparent-headed household
- Illnesses/health issues of grandmothers
- Pivotal role of community health clinics
- Sources of stress
- Sources of strength
- Poor education levels
- Resources in community
- Concern about dying before grandchildren's futures are secure/mapped out
- Talking about sex to grandchildren
- HIV/AIDS – consequences of unprotected sex
- Drugs/rebellion – mechanism for dealing with unknown HIV status
- Lack of psychosocial support for grandparents
- Ubuntu demonstrated by grandmother
- Income generating skills and knowledge
- Needs of grandparents

Initial list of categories:

- Abandonment by surviving parent of single orphans
- Circumstances under which grandparents took on guardianship
- Stress and sources of stress
- Sex and HIV/AIDS
- Needs of grandparents
- Orphans needs
- Spirituality of grandparents

Major categories:

- Circumstances under which grandparents took on guardianship of grandchildren
- Grandparents' stressors
- Sex and HIV/AIDS

- Needs of grandparents with regard to caring for grandchildren
- Orphans' needs
- Spirituality of grandparents

B. Major categories extracted from other focus groups and case studies

Orphan focus group	Stakeholder focus group	GAPA Case Study	Khayelitsha family case study	Soweto family case study
1. Absence of surviving parent of single orphans	1. Government support of & involvement in grandparent-headed households	1. Key aspects/thrusts of programme	1. Precipitating factors leading to grandparent-headed households	1. Assuming parenting role over grandchildren
2. Multiple losses suffered by orphans	2. Support role of churches	2. Profile of grandmothers accessing programme	2. Challenges/stressors faced by these households	2. Grandmother's greatest challenges
3. Symbiotic relationship between grandparents and orphaned grandchildren	3. Stressors and needs of grandparents	3. Significant challenges experienced by grandparents	3. Agency responses to these challenges.	3. Needs of grandmother
4. Ubuntu demonstrated by orphans	4. Stressors/challenges experienced by grandchildren	4. Needs of grandparent-headed households	4. Sex/HIV/AIDS	4. Tangible help from supporting agency
5. Needs of grandparent caregivers	5. Empowering/equipping/training of grandmothers	5. needs of orphaned grandchildren	5. Symbiotic relationship between grandparents and grandchildren	5. Support role of other adults in household
	6. Challenges with regard to working with grandparents	6. Lessons learnt	6. Strengths of grandparents &	6. Needs of orphans

			grandchildren	
	7. Resilience of grandmothers	7. Needs of supporting agencies	7. On-going needs of grandparents and grandchildren	7. Impact of parents' death on orphans

C. THEMES FROM EMPIRICAL STUDY

1. PRECIPITATING FACTORS LEADING TO GUARDIANSHIP OF GRANDCHILDREN
2. STRESSORS/CHALLENGES EXPERIENCED BY GRANDPARENTS AND GRANDCHILDREN
3. ONGOING NEEDS OF GRANDPARENTS AND ORPHANED GRANDCHILDREN
4. RESILIENCE OF GRANDPARENTS AND ORPHANED GRANDCHILDREN
5. EXTERNAL SUPPORT AVAILABLE TO GRANDPARENT-HEADED HOUSEHOLDS

'Granny scam' costs millions

Students lie about home life to get study loans

PREGA GOVENDER

UNIVERSITY students are robbing the government's financial aid scheme of millions of rands — by fraudulently using their grandmother's pension details to qualify for study loans.

The National Student Financial Aid Scheme, set up to help the country's neediest students, caters mainly for families who cannot afford to contribute anything towards their children's tertiary education.

But thousands of students who do not qualify for the scheme — because their parents earn above the limit of R122 000 a year — are cheating the system by submitting sworn affidavits to universities declaring that they are supported by their poverty-stricken grannies.

The government funding scheme dished out loans totalling more than R2.3-billion to 153 000 students in the 2008/09 financial year. Universities around South Africa this week confirmed that many of these students were going "the granny route" to secure loans.

A first-year student from the University of KwaZulu-Natal said she did not feel guilty about lying about living with her granny in order to secure a loan. "My parents were aware that I had given my granny's details. I was forced to go this route as I otherwise would not have qualified. Maybe I will feel guilty if I don't succeed with my studies."

Universities have told a ministerial task team — appointed by the minister of higher education, Blade Nzimande, to review the student funding scheme — that student fraud was "quite a serious problem".

At some universities, more than

half the students applying for loans claimed to have no family income to contribute to their studies.

The combination of fraud and the low-income threshold leaves top students battling to finance their studies or having to settle for meagre amounts in financial aid.

The chairman of the ministerial task team, Professor Malusi Balintulo, who is vice-chancellor of Walter Sisulu University in the former Transkei, said there was "plenty of evidence that students, who otherwise might not qualify

because of family income, try all kinds of tricks to beat the system".

Roekus de Villiers, director of financial aid at Tshwane University of Technology, said if the problem was rooted out, "we will be very surprised to see how much funding we actually have for our deserving students".

Between 85 and 90% of the 15 000 students at his university who had been given loans had claimed to have a "zero expected family contribution", implying that they qualified for the maximum loan of R47 000 — something De Villiers said he found difficult to believe.

"Most of these students' parents work for the government. Fraud is a problem but we don't have the capacity to deal with it," he said.

Graham Renecke, head of the financial aid office at the Cape Peninsula University of Technology, said: "The lie factor is problematic, because you're never really sure if those that claim to be needy are indeed that needy."

Experts and parents say the government also needs to raise the income threshold for funding.

Johannes Vorster, a civil servant employed at the Buffalo City municipality in East London, said financial assistance from the government for middle class families would "make a huge difference".

"Middle class parents are really battling to put their children through university. I have to spend between R4 500 and R5 000 on my son every month," Vorster said.

Professor Ihron Rensburg, vice chancellor of the University of Johannesburg, said the threshold ought to be increased to R300 000 over the next three to five years.

A spokesman for the scheme, Bonny Feldman, said: "We are aware that there are some people who cheat, but we also don't think that it's an enormous number."

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How a study loan is granted

THE national means test for study loans looks at factors such as where the student lives, the family income and the number of people in the house dependent on it.

The number of students in the household and the cost of study is used to calculate an expected family contribution.

Universities use the expected family contribution to decide on the amount of the loan awarded to a student.

• A family with an income of R64 000 a year with four dependants will qualify for a loan of up to R47 000, depending on the funds available to the university.

• A family with an annual income of over R121 000 with three dependants would have to pay R14 774 towards each child's university costs, which includes tuition fees, accommodation, meals, textbooks and other study material.