

**AN EXPLORATION OF THE IMPACT OF AIDS-RELATED LOSSES AND ROLE
CHANGES ON GRANDMOTHERS**

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ABSTRACT

The US Bureau of the Census (1999) projected that by 2004, 14 million people in sub-Saharan Africa will develop full blown AIDS, making this region by far the largest disease burden in the world (World Health Organization, 2002). The United Nations AIDS Programme judged South Africa to have the leading number of people living with HIV/AIDS worldwide (World Health Organisation, 2002). To date there has been extensive research conducted on the socio-economic impacts of HIV/AIDS on families in Africa. However an area of investigation that has remained largely underreported is the inquiry into the psychological impacts of HIV/AIDS on elderly caregivers. In African families older women increasingly have to provide care to their adult children with AIDS and their orphaned grandchildren. However few research studies have assessed the experience of parental caregiving and its psychological impacts on these women. This qualitative research study hypothesised that the role of primary parental caregiver in fact causes a range of psychologically distressing states, which serve to compromise the psychological well-being of these caregivers. To investigate this hypothesis three Xhosa speaking women living in informal settlements in Grahamstown, in the Eastern Cape Province of South Africa were selected for the study. The women were interviewed by means of semi-structured interviews, which consisted of questions related to their caregiving experiences, their experiences of loss, their choice of coping strategies, the role of support networks and their experiences of foster care responsibilities. The interviews were transcribed and analysed using a grounded hermeneutic approach. The research results confirmed the working hypothesis. The research revealed that although it was considered culturally appropriate for older women to care for their children and grandchildren, their caregiver roles caused significant psychological distress. Their distress was related to: emotional and physical exhaustion, complicated grief

reactions and ongoing emotional and physical upheaval related to foster care responsibilities. Based on the results, the research recommendations emphasised the need for continual awareness of the psychological implications of caregiving for older African women with the aim to preserve their capacity to function as the primary caring resource to families struck by HIV/AIDS.

TABLE OF CONTENTS

CHAPTER ONE: Introduction	1
CHAPTER TWO: Literature Review	3
2.1 Caregiving to adult children with AIDS	5
2.1.1 Caregiving responsibilities	5
2.1.2 Emotional impacts of HIV/AIDS caregiving	6
2.1.3 Stigma and secrecy associated with HIV/AIDS	7
2.1.4 Anticipatory grief	8
2.2 Loss of an adult child	9
2.2.1 Bereavement and grief	9
2.2.2 Complicated grief	10
2.2.2.1 Attachment to and relationship with an adult child	11
2.2.2.2 Situation surrounding the death of an adult child	12
2.2.2.3 Social factors associated with AIDS-related death	13
2.3 Ways of coping with death	14
2.3.1 Hope and denial	14
2.3.2 Religious beliefs	15
2.3.3 Talking about death and expressing grief	15
2.4 Support networks	16
2.5 Grandparental foster care	17
2.5.1 Importance of family foster care	18
2.5.2 Impacts of grandparental foster care	18
2.6 Motivation for the research and the research hypothesis	20

CHAPTER THREE: Methodology	22
3.1 Aim of the study	22
3.2 Sample	22
3.3 Data collection	24
3.4 Creating the semi-structured interviews	24
3.5 Data analysis	25
3.6 Analytical procedure	26
3.7 Ethical considerations	27
3.7.1 Information and consent forms	27
3.7.2 Privacy, anonymity and confidentiality of data	27
 CHAPTER FOUR: Results	 29
4.1 Routes to parental caregiving	29
4.1.1 Cultural appropriateness	29
4.1.2 There is nobody else	30
4.2 Responses to the caregiving role	31
4.3 Parental caregiving	32
4.3.1 Physical exhaustion	32
4.3.1.1 Multitude of tasks	32
4.3.1.2 Lack of assistance	33
4.3.1.3 Physical demands	33
4.3.2 Emotional exhaustion	33
4.3.2.1 Shock	34
4.3.2.2 Distress	34
4.3.2.3 Loneliness and sadness	35
4.3.2.4 Anger	35
4.3.2.5 Helplessness	36
4.3.2.6 Fear	36

4.3.3 Stigma associated with HIV/AIDS	37
4.3.3.1 Fear of infection	37
4.3.3.2 Shame	37
4.4 Losing an adult child to AIDS	38
4.4.1 Anger	39
4.4.1.1 Meaninglessness	39
4.4.1.2 Unfairness	39
4.4.1.3 Secrecy	39
4.4.1.4 Self-blame and guilt	40
4.4.2 Sadness	41
4.4.3 Worry	41
4.4.4 Hopelessness	42
4.4.5 Regret	42
4.4.6 Relief	43
4.5 Caregivers' coping strategies	43
4.5.1 Hope	44
4.5.2 Belief in God	44
4.6 Support offered to caregivers	46
4.6.1 During caregiving	47
4.6.1.1 Hospice	47
4.6.1.2 Neighbours	47
4.6.1.3 Church	47
4.6.2 Immediately after children's death	47
4.6.2.1 Church	48
4.6.2.2 Family	48
4.6.3 Long-term	48
4.6.3.1 Church	48

4.7 Responses to orphaned grandchildren	49
4.7.1 Willingness	50
4.7.2 Reluctance	51
4.7.2.1 Emotional strain	51
4.7.2.2 Physical strain	54
CHAPTER FIVE: Discussion	56
5.1 During caregiving	56
5.1.1 Routes to parental caregiving	56
5.1.2 Experience of caregiving	57
5.2 During bereavement	60
5.2.1 Participants' grief reaction	60
5.2.2 Participants' way of coping with death	62
5.2.3 Support during bereavement	62
5.2.4 Responses to grandparental foster care	63
CHAPTER SIX: Conclusion	65
6.1 Limitations of the study	65
6.2 Recommendations	66
APPENDIX ONE	68
REFERENCES	72

LIST OF FIGURES

Figure 1: Causal factors to becoming a parental caregiver	29
Figure 2: Response to parental caregiving	31
Figure 3: Factors which contribute to physical exhaustion	32
Figure 4: Participants' experience of emotional exhaustion	34
Figure 5: Participants' grief reaction	38
Figure 6: Coping strategies	43
Figure 7: Nature and sources of support according to three time periods	46
Figure 8: Participants' responses to foster care	50

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CHAPTER ONE

INTRODUCTION

There are unprecedented numbers of HIV/AIDS infected individuals and AIDS orphans living in sub-Saharan of which South Africa is one of the leading areas of burden. African people infected with HIV/AIDS predominantly return home for care during the end stages of their illness bringing their children with them. Older mothers respond to their children and grandchildren's care needs by taking up the role of parental caregiver. To date much emphasis has been placed on the social, material and economic impacts of HIV/AIDS on families while far less attention has been given to the psychological repercussions of HIV/AIDS on families and in particular on caregivers. There is a growing need for policies and organisation to respond not only to the socio-economic needs of elderly caregivers, but also to their psychological needs. This research aims to contribute to new research interests that highlight the psychological implication of multiple AIDS-related losses for older caregivers and the subsequent role shifts they encounter. From this motivation the study sets out to explore the impact of AIDS-related losses on three African women in Grahamstown in the Eastern Cape Province of South Africa. The working hypothesis is that these women experience psychological distress in their caregiver roles despite the fact that they feel compelled to fulfil caregiver duties due to intergenerational support which is a customary part of the African family network.

This study is structured as follows. Chapter one outlines literature and other recent research studies, which have addressed the issues of HIV/AIDS and the multiple impacts it has on families in Africa. Additionally the chapter delineates what constitutes the HIV/AIDS caregiver role within African families specifically in relation to infected adult children and orphaned grandchildren. Next literature on loss and bereavement is presented in relation to themes associated with the death of an adult child and the potential for parental complicated grief reactions. This chapter additionally outlines ways of coping with loss and the importance of support networks in grief resolution. Finally a section is presented highlighting the motivation for the study and the research hypothesis.

The research methodology is presented in chapter two. This includes the aims of the study, the research questions, a description of the sample, data collection methods and the research methodology used to analyse the data. Finally a section discussing ethical considerations is presented.

Chapter three, the results section, presents the research findings according to: the routes to parental caregiving, responses to this role; experiences of caregiving; experiences of loss; coping during caregiving and after loss; the role and nature of support and responses to orphaned grandchildren and foster care responsibilities.

In chapter four the research findings are evaluated and interpreted with respect to the research hypothesis. Additionally the similarities and differences between the research results and other research are explored.

The concluding chapter presents a summary of the main research findings, limitations of the research and recommendations for further research and action.

CHAPTER TWO

LITERATURE REVIEW

According to the World Health Organisation and the United Nations AIDS Programme (UNAIDS) 40 million people were living with HIV/AIDS at the end of 2001 and more than 20 million have died from AIDS since the first clinical evidence was reported in 1981 (World Health Organisation, 2002). United Nations data further reveal that 84% of the estimated cumulative adult and child HIV/AIDS-related deaths have occurred in the sub-Saharan African region, and seven out of every ten new HIV infections will occur in this area (World Health Organisation, 2002). The US Bureau of the Census (1999) projected that by 2004, an additional 14 million HIV-infected people in sub-Saharan Africa will develop full blown AIDS, making it by far the largest disease burden of all world regions (World Health Organisation, 2002). According to UNAIDS, South Africa has the largest number of people living with HIV/AIDS in the world (UNAIDS, 1999).

The African ethos of caring and sharing known as *ubuntu* has crucial implications for the elderly population throughout sub-Saharan Africa, as African families are facing a crisis due to the unprecedented HIV/AIDS statistics in this region (Cattell, 1997). It is commonly assumed that the extended family in Africa provides a safety net for individuals in times of need (Seeley & Kajura, 1993). The extended family unit traditionally held the responsibility for all services to their members whether social or economic (Seeley & Kajura, 1993). This custom of shared support within the extended family stemmed from the cultural philosophy of *ubuntu* and assured that the sick; the old and the young were cared for within their families. *Ubuntu* ideals therefore serve to bind African families together. They emphasise the group over the individual and value connectedness between all people. This interdependence is expressed in a person's daily behaviour towards others and in particular between family members (Cattell, 1997). These ideas about life and living are found in all African cultures (Cattell, 1997) and in practical everyday terms they mean that family members are expected to rely on and to support each other within the African family system of shared social support. This interdependence between family generations is best demonstrated in the commonly found African family relational system of older children caring for younger children, adult brothers and sisters helping each other, grandmothers caring for grandchildren and young adult family members caring for the elderly (Cattell, 1997). However since the

rapid increase of HIV/AIDS infection in Africa the extended family has been under extraordinary pressure to sustain their capacity to care for its members. Everywhere in Africa families are having increasing difficulty coping with the daily needs of their family members (Cattell, 1997). The HIV/AIDS epidemic places a particularly heavy burden upon the capacity of the family to continue to provide care (Seeley & Kajura, 1993). AIDS in Africa primarily strikes the middle-aged generation, leaving behind the old and the young without the crucial support of their family's most productive members. Older family members – in particular grandmothers - are being left to maintain their family's capacity to care at great cost to their own emotional and physical well-being.

Although research has noted that HIV/AIDS is leading to a devastation of individual and family life, the impacts on and experiences of older people have largely remained unreported (Paul, 2002). Recently there has been a growing research interest in addressing the needs of the elderly in contexts such as HIV/AIDS, as it is becoming increasingly apparent that older people play the central role in sustaining households which have been devastated by AIDS (Ankrah, 1993; Foster & Makufa, 1997; Hunter, 1990). HelpAge International, a leading global network encouraging research and action on ageing, has noted that the HIV/AIDS greatly affects the lives of the elderly in multiple ways (HelpAge International, 2001). The growing responsibility of older parents in Africa is two fold: First, older parents are frequently obliged to look after adult children who are infected with AIDS and who will eventually die (Mupedziswa, 1997). In addition adult children often expect elderly parents to care for them with extremely limited resources. Second, elderly parents are obliged to look after the grandchildren left behind by their sons and daughters who die of AIDS (Mupedziswa, 1997). Literature reveals that caregiving responsibilities are experienced with significant degrees of emotional turmoil as a result of chronic exhaustion, grief, worry due to financial upheaval, lack of knowledge and resources for dealing with adult children with AIDS, conflicts with grandchildren, social stigma, discrimination and lack of support (Paul, 2002).

In particular older women are being affected by the burdens associated with caregiving since in many cultures it is traditionally the women's role to care for sick members in the family (Saengtienchai & Knodel, 2001, World Health Organization, 2000, 2002). A mother is socialised to fulfil a different role to that of the father. She is expected to be the nurturer and the caregiver of the family and is accustomed to carrying the family's emotional burdens. For

the most part women have been socialised to believe that it is their duty to create a family circle (Sanders, 1989). This tradition is exemplified by the numerous older women in South Africa taking up the role of parental caregiver to their adult children with AIDS and their orphaned grandchildren. To be called mother in the African family brings many obligations (Cattell, 1997). Cross (2001) found that amongst impoverished households struck by HIV/AIDS women carry most of the household burdens and hold the overall responsibility for their children and their children's children. It is not likely that the African family system will disintegrate due to the AIDS crisis (Cattell, 1997) however it is evident that it's survival comes at great cost to Africa's elderly women.

The ideals of *ubuntu* are one thing, dealing with practical realities another. The literature below outlines research conducted on how older women experience their caregiver role in their everyday lives and how this role impacts on them emotionally, physically and practically.

2.1 Caregiving to adult children with AIDS

Four aspects of caregiving to an adult child with AIDS are presented. First caregiving responsibilities, second emotional impacts of this role; third how stigma and secrecy associated with HIV/AIDS exacerbates caregiving and finally the function of anticipatory grief in caregiving.

2.1.1 Caregiving responsibilities

Research has found that parental caregivers of adult children with AIDS aspire to provide unconditional love and attention for their children around – the – clock, as taxing as this is on their own well-being (World Health Organisation, 2002; Saengtienchai & Knodel, 2001). In HIV/AIDS caregiving a parent's hope is to provide sufficient comfort for their child, to demonstrate love, to ease their child's pain and anxiety about death, to provide dignity in their suffering and to overall facilitate a peaceful death (World Health Organisation, 2002). However in recent research it is apparent that elderly women typically experience their caregiving responsibilities for their children with AIDS as exhausting (Saengtienchai & Knodel, 2001; World Health Organisation, 2000; 2002). When an adult child returns home at the terminal stage of their AIDS illness, caregiving involves a wide variety of tasks which are

particularly demanding on an older parent (Saengtienchai & Knodel, 2001). As a result caregivers often experience their lives as complex and arduous and feel overwhelmed by the responsibilities they inherit after their sick children return home (Paul, 2002; World Health Organisation, 2000). Parents have to adjust their lives to accommodate the many aspects of the caregiving role and the subsequent role shifts it involves. Due to the vast majority of HIV/AIDS infected individuals being in their middle-age an increasing number of older people face the loss of support they might have expected to receive from their adult children in the future (Paul, 2002; Williams & Tumwekwase, 2001). Parental caregiving therefore represents a reversal in family caregiving roles, as under usual circumstances elderly people would look forward to being cared for by their adult children and not vice versa. However despite the hardship caring for a child with AIDS brings and the multiple losses their deaths represent elderly women consider it to be their duty to provide care to their children regardless of the compromise this has on their own emotional and physical health (World Health Organisation, 2000).

2.1.2 Emotional impacts of HIV/AIDS caregiving

Providing care to a terminally ill and physically weak person can result in multiple forms of psychological, physical and social stress for a parental caregiver (Saengtienchai & Knodel, 2001). The stress of caring for a person dying with AIDS is particularly challenging. Peabody (1986) wrote after caring for her son who died of AIDS, that daily life with AIDS as a caregiver does not fit into words easily. AIDS, which is called a wasting disease, causes emotional devastation for a mother (Peabody, 1986). A child's physical erosion is their parent's emotional erosion. Peabody (1986) stated that words such as fear, panic, despair, horror, frustration, anger and hysteria together still do not adequately describe this caregiving experience. AIDS wastes an individual from a once strong and independent person, to a gaunt, fumbling, shuffling, confused, incontinent person and in this way AIDS is a viciously cruel and humiliating disease to witness (Peabody, 1986). It is emotionally wrenching for a parent to realise that an adult child has AIDS, a debilitating and fatal illness, and to observe the progressive decline in that child's physical and mental condition which is accompanied by severe suffering (Peabody, 1986). It is not suffering as such that is most deeply feared by people but suffering that degrades (Sontag, 1988). AIDS leads to a hard death, it is a disease not only terrifying because it is lethal but because it is dehumanising.

2.1.3 Stigma and secrecy associated with HIV/AIDS

Stigma and secrecy surrounding HIV/AIDS are factors which exacerbate a caregiver's emotional distress, and add noticeably to the overall stress of caregiving (McDonell, Abell & Miller, 1991). Shame, guilt and blame are commonly associated with AIDS. The unsafe behaviour that produces AIDS is judged to be delinquent and deviant and most people consider the sexual transmission of the illness as a tragedy one brings upon oneself (Sontag, 1988). In this light AIDS is frequently viewed as a punishment. Furthermore people generally respond with fear and avoid those who pose a potential threat to their health and safety. To the extent that AIDS is contagious, fatal, and incurable, many people hesitate to interact with those who are associated with it (Leary & Schreindorfer, 1998). The stigma stemming from shame and contagion fear is mostly described in the literature in relation to the HIV positive individual while the caregiver's experience of stigma frequently goes unreported. However being associated with a stigmatised person is in itself often viewed as grounds for being stigmatised (Leary & Schreindorfer, 1998). Therefore it follows that AIDS caregivers typically experience the same forms of stigmatisation as do HIV/AIDS sufferers.

The stigma associated with HIV/AIDS and the fear of negative reactions from friends and neighbours, results in parental caregivers feeling reluctant to share their feelings or to seek emotional support from their usual support networks whilst caregiving (Dane, 1991). Being avoided or rejected is a common but painful experience for AIDS caregivers and a range of negative emotions are evoked when it occurs, such as depression, hostility, anger, anxiety, feelings of exclusion, isolation, estrangement, alienation and loneliness (Leary & Schreindorfer, 1998). The psychological stress for a family caregiver is all the more so when their child's illness is socially stigmatised as in the case with HIV/AIDS. The very reputation of an illness can add to the suffering of those associated with it (Sontag, 1988).

Dane (1991) observed that parental grief is most acute at three points when faced with a child's AIDS diagnosis. These are: when the diagnosis is disclosed, when the serious symptoms appear and at the terminal stage of the illness. However research has found that many parents learn of their child's diagnosis only when the serious symptoms appear and therefore the first two stages outlined by Dane often coincide (Saengtienchai & Knodel, 2001). This is found to be particularly the case when adult children, who have been residing

elsewhere, have learnt of their diagnoses themselves at an earlier point but because of the stigma surrounding the disease have chosen to conceal their status from their parents for as long as possible. Young adults are frequently secretive about their HIV/AIDS status as they fear being rejected by their families. The result however is that parental grief is acute at a child's homecoming as it is then that a parent first learns of the terminal nature of their child's illness and are faced with their child's advanced physical deterioration.

Stigma and the subsequent secrecy around HIV/AIDS does not only cause negative impacts on caregivers alone but it is also considered the greatest barrier to effective care for people living with the disease from all health care providers (World Health Organisation, 2000). A health care worker involved in research done by the World Health Organisation responded to secrecy around HIV/AIDS by saying, "The HIV status should be known. But as long as we (the health care workers) continue to be secretive then we will role model this to people, families and communities. People are dying in secrecy" (World Health Organisation, p. 31, 2000).

2.1.4 Anticipatory grief

As thus far highlighted parental caregiving for an adult child with AIDS is an emotionally complex and draining experience. An additional aspect of caregiving, which parents must endure, is the anticipation of their loss. Despite the hopes of families to prevent an inevitable death, an anticipatory grieving process invariably begins before death (Dane, 1991). Anticipatory grief refers to grief which occurs prior to death and is typically observed in situations where individuals are aware that death is inevitable, such as in the case of caregiving to a person suffering with a terminal illness (Dane, 1991). Anticipatory grief is a controversial topic in the literature as some authors believe that the concept is too narrow and does not adequately address the complex nature of loss and that it is not the primary experience in caregiving, while others value its contribution to more adaptive coping during the grief process which continues after death (Brown & Powell-Cope, 1993; Dane, 1991; Spiegel, 1977; Worden, 1991). Despite these debates the general agreement is that sudden, unexpected death produces prolonged grief and complicated bereavement, which consists of excessive physical and emotional trauma (Sanders, 1989). Studies on the impact of sudden deaths have found that there is certainly value in some preparation for loss (Worden, 1991). In relation to parents who face the loss of a child to a terminal illness, the assumption is that

family members have an opportunity to utilise the anticipatory grief process to work on preparing themselves for the many changes invariably associated with their loss, before it actually occurs and therefore are better fortified to deal with its final impact (Dane, 1991). In specific relation to AIDS however, the relatively short average life expectancy of persons with AIDS makes it difficult for caregivers to escape the pervasiveness of loss (Dane 1991). Furthermore a sense of untimeliness always occurs when faced with the death of a child, which undermines a parent's attempts to prepare themselves for their loss (Brown & Powell-Cope, 1993; De Vries, Lana & Falck, 1994; Sanders, 1989). Dane (1991) outlined different ways in which parents respond to and cope with their children's AIDS diagnosis and the anticipation of their loss. Some remain shocked and struggle to understand it or accept it, some feel God is punishing them, some deny the reality of it and some feel responsible for their child's impending death. A parent's sense of responsibility occurs when parents confront the fact that they cannot undo the tragedy of their children's inevitable death but must live with anguish as they await their loss (Dane, 1991). Anticipatory grief, albeit a beneficial process, does serve to contribute to the range of distressing emotions felt by parents who provide care to children suffering with terminal illness.

In sum therefore, the literature highlights that parental caregiving to an adult child with AIDS is emotionally and physically demanding. For African mothers who have limited resources these demands are hard felt and render them vulnerable to a range of physical and psychological conditions in response (HelpAge International, 2000).

2.2 Loss of an adult child

To study the experience of losing an adult child first literature on parental grief and bereavement is presented followed by a commentary on what constitutes complicated grief reactions and the factors which potentially arrest grief resolution.

2.2.1 Bereavement and grief

Bereavement and grief are two terms that are often used interchangeably when referring to the pain experienced after a loss of some sort (Sanders, 1989). While one may understand what is meant when each term is used it is important to operationalise them. Bereavement represents the experiential state one endures after realising a loss has occurred and that it is an

objective fact (Kastenbaum, 1977 cited in Sanders, 1989). Bereavement is often used as a blanket term to describe the vast array of emotions, experiences, changes and conditions that take place as a result of a loss (Sanders, 1989). While bereavement represents the state of loss, grief represents the particular reactions one experiences while in that state (Sanders, 1989). There are widespread responses or symptoms experienced as grief which include, to name a few, anger, guilt, despair, sadness, helplessness, hopelessness, anxiety, shock, yearning, physical complaints such as body ache and weakness, sleep and appetite disturbances, dizziness and agitation (Engel, 1961; Klass, 1988; Kubler-Ross, 1969, 1975; Sanders, 1989). Freud (1917) in his paper *Mourning and Melancholia* wrote that grief follows upon every loss with the symptoms varying among individuals and the outcome being either adaptive or debilitating but what is certain is that every person is affected by the experience of loss (cited in Sanders, 1989).

The process of bereavement involves steps through which a bereaved individual must progress before their grief reaction can be resolved. Several authors have referred to and agree that bereavement runs a consistent course (Engel, 1961; Klass, 1988; Kubler-Ross, 1969, 1975; Sanders, 1989; Spiegel, 1977; Worden, 1991). The only differences between authors are the terms they use to describe the phases of grief and the number of phases they delineate before grief resolution is considered.

2.2.2 Complicated grief

Sometimes a person may find it difficult to resolve their feelings associated with their loss or find grief arrested in a particular phase rendering them unable to progress towards grief resolution. These experiences signify complicated grief reactions. The term *complicated grief* is used where there are difficult factors surrounding a death, which may stem from: the attachment to the deceased and the nature and quality of the lost relationship and the situation and social factors surrounding the death (De Vries, Lana & Falck, 1994; Sanders, 1989; Worden, 1991). When adult children die of AIDS parents typically confront a number of factors associated with these attributes of their loss, which in turn serve to complicate their grief reaction and prolong their bereavement state. This is outlined below.

2.2.2.1 Attachment to and relationship with an adult child

The strength of the attachment formed between the bereaved and the deceased significantly affects both the intensity of bereavement and the time it takes for the completion of the grief process (Bowlby, 1980 & Parkes, 1971 cited in Sanders, 1989). Bowlby's attachment theory describes how the loss of an important attachment greatly affects the safety and security of a bereaved person (Worden, 1991). Furthermore if the relationship with the deceased is characterised by ambivalence, guilt, hostility or dependency the bereaved person's grief reaction will be complicated (Sanders, 1989). Due to the multiple aspects of the bond between a parent and child, the death of a child has many complex responses from a parent (Moss, Leshner & Moss, 1986). The intensity and duration of their grief is profound. Gorer (1965) wrote "the most distressing and long-lasting of all griefs, it would seem, is that of the loss of a grown child. In such a case it seems to be literally true, and not a figure of speech, that the parents never get over it" (cited in Moss, Leshner & Moss, 1986, p. 212). With the loss of an adult child parents lose future expressions of their values and ideals and they experience a loss of continuity as they lose their connection to the future through their children. They must face their dreams being left unfulfilled and plans unrealised (De Vries, Lana & Falck, 1994; Moss, Leshner & Moss, 1986). The death of an adult child robs a parent of their future security, with a child's death representing the loss of their future sources of support.

In old age parents are to some extent prepared for the normative losses which accompany old age such as the loss of a spouse, loss of health, loss of siblings, loss of income, loss of independence (Moss, Leshner & Moss, 1986). The fact that these losses are normative does not imply that they are experienced with ease. Normative losses can in themselves be very problematic. However with the addition of "off-time" losses such as in the case of the death of a child, the probability of older parents experiencing psychological disorders such as depression and anxiety is significantly increased (Moss, Leshner & Moss, 1986). The untimeliness and unnaturalness of a child dying before a parent severely complicates grief (De Vries, Lana & Falck, 1994; McGoldrick & Walsh, 1991; Mize, 1975; Moss, Leshner & Moss, 1986; Sanders, 1989). The death of a child at any age is always considered untimely. When a death departs from the natural order of human life expectancy the interruption is associated with a view that the world is random and unreliable (De Vries, Lana & Falck, 1994). The death of a child is the most noteworthy example of this. The impossibility of surviving a child remains foremost in parents' thoughts in their grief as they ruminate over

“why”. Parents search for meaning against the overriding feeling that life no longer makes sense. One of the most difficult tasks for parents, which is also the most important in grief resolution, is the search for some meaning in their child’s death (Sanders, 1989). The meaninglessness of a child’s death causes parental grief to regularly be characterised by confusion, conflict and despair. It is often here that parents turn to religious beliefs in an attempt to find an explanation for their loss. Religious beliefs frequently become stronger in parental bereavement as parents try to cope with and understand their loss (Sanders, 1989).

An additional factor associated with parental grief, which complicates bereavement, is the profound guilt which accompanies their grief. When a child dies whether by accident or illness parents always feel responsible (Sanders, 1989). Implicit in this is the belief that if they had fulfilled their parental duty their child’s death would not have occurred. The sense of parental obligation to protect one’s child is violated with a child’s death (Klass, 1988). Parental-bereavement-guilt is evoked despite the cause of death or the reality that a parent could not have saved their child. Their guilt is in response to the violation of the deep sacred belief that a parent’s duty is to protect one’s child. Parental-bereavement-guilt is predominantly two pronged: Illness-related guilt, which involves parents feelings that they did not provide adequate care to their child during illness or at the time of death and survival guilt, which relates to the parental belief that it goes against the nature of things to survive one’s child (Sanders, 1989). Guilt is a significant feature of complicated grief.

A griever’s complicated grief reaction may manifest in chronic, delayed, exaggerated or masked grief (Worden, 1991). Parents who lose adult children to AIDS are vulnerable to such grief reactions owing to the aforementioned factors associated with their attachment to and relationship with their adult children.

2.2.2.2 Situation surrounding the death of an adult child with AIDS

The opportunity for parents to participate in the care of their children prior to death has been identified as a facilitating factor in grief resolution (McGoldrick & Walsh, 1991). This is because it offers parents the opportunity to utilise the time prior to death to prepare themselves for their loss. The value of this has been outlined in the section on anticipatory grief (noted in 2.1.4). However many children with AIDS return home in advanced stages of terminal illness (Saengtienchai & Knodel, 2001). On the whole parents who first learn of

their child's HIV/AIDS diagnosis find themselves preoccupied with tremendous shock during the initial period spent with their child. Furthermore the rapid decline of individuals in advanced stages of AIDS illness results in a child's homecoming generally being short lived. Therefore the quality and duration of the time spent with children in the end stages of AIDS illness causes a parent's capacity to utilise their caregiving time in preparation for their loss to be significantly reduced.

2.2.2.3 Social factors associated with AIDS-related death

The grief process following the death of a person from AIDS is difficult because of the widespread societal stigma and condemnation of the illness and those associated with it. The stigma, the fear of infection and the physical disfigurement accompanying HIV/AIDS results in AIDS generally being considered a socially unspeakable disease. This results in high incidences of secrecy around HIV/AIDS and those who suffer with it. Lazare (1979) highlighted that when a loss is socially unspeakable, grief reactions are most likely complicated (cited in Worden, 1991). Bereaved reactions are strongly influenced by the dynamics of social attitudes. The struggle with fear of rejection can overwhelm a griever's capacity to cope with their loss in that it often leads to feelings of helplessness and depression (Dane, 1994). Stigmatised grievers frequently keep their grief, guilt, shame and anger to themselves causing them to experience disenfranchised grief (Dane, 1994). Disenfranchised grief refers to grief that a person experiences after a loss which cannot be openly acknowledged, publicly mourned or socially supported (Ingram, Jones & Smith, 2001). Death from AIDS profoundly alters grievers' social relationships as a consequence of real or imagined stigma and healthy resolution of grief is undermined (Dane, 1994).

The loss of an adult child is a specific type of loss suffered by a family (De Vries, Lana & Falck, 1994), and parental grief is associated with specific features related to this loss. If parental grief following the death of an adult child in addition includes features associated with HIV/AIDS-related issues, parents are left increasingly vulnerable to complicated grief reactions (Dane, 1994).

2.3 Ways of coping with death

Various ways of coping with loss are widely addressed in death and dying literature. Parental bereavement literature, which includes literature on parental caregiving to adult children with AIDS, notes that parents frequently use hope, denial, religious beliefs and practices as coping strategies during periods of caregiving and after the death of a child. These coping strategies are presented below in addition to a section that outlines the value of expressions of grief in achieving grief resolution.

2.3.1 Hope and denial

Parents may respond with hope and denial when they receive news that a child has a terminal illness. These are useful and appropriate ways of coping initially, especially when months of caregiving await a parent. Hope that a child will get better helps a parent's morale during the period of illness and is a source of motivation for them to provide the best care possible (Saengtienchai & Knodel, 2001). Hope sustains parents through the otherwise intolerable experience of witnessing the gradual death of a child. Hope is often reflected in a parent's search for treatments that can somehow improve their child's health (Saengtienchai & Knodel, 2001).

Hope also allows parents to deny the reality of their pending loss. Denial functions as a buffer after unexpected shocking news and it allows parents to collect themselves (Kubler-Ross, 1969). It is a healthy way of dealing with uncomfortable and painful situations. After receiving the news that a child is going to die it is an appropriate psychological response to consider the possibility of their death and then to put it aside in order to pursue life (Kubler-Ross, 1969). With time however other less radical defences are mobilised, as denial is usually a temporary defence that is soon replaced by partial acceptance (Kubler-Ross, 1969). In almost all patients and their families anxious denial follows the news of terminal illness and is used again and again throughout the period of illness. Psychological denial functions as a way of protesting the reality of death by keeping the news out of consciousness since in our unconscious mind we are immortal and it is almost inconceivable for us to acknowledge that we have to face death (Kubler-Ross, 1969). However denial is rarely maintained throughout the period of illness as increased awareness gradually occurs when the reality of the loss comes into fuller consciousness (Kubler-Ross, 1969). This is an important characteristic of

the process of grief and is important in the progression towards grief resolution which ends with a state of acceptance. As denial is gradually relinquished a number of very painful emotions are evoked such as anguish, despair, depression, hopelessness, anger and guilt. (Dudley, 1992) Grief is not a static condition rather it is a constantly changing process that moves from initial denial and avoidance to gradual recognition and acceptance (Dudley, 1992). The very nature of this process allows griever to survive their bereavement experience psychologically intact and initial denial is a valuable contributor to this process.

2.3.2 Religious beliefs

Trusting in the power of God empowers many people who meet the pain of grieving loss. Faith in God has been identified as a significant feature that enables people to cope with negative life events (Klass, 1988). Caregivers who have limited resources and few support options frequently turn to religion for solace and understanding and experience their religion as their only source of comfort (World Health Organization, 2000). Belief in God facilitates making sense of circumstances which many parents find as the most difficult bereavement task. The belief in God, which includes belief in divine providence, therefore assists parents to accept the loss of a child as belief that God has a plan beyond the comprehension of humans' means that life is not random. With the death of a child a parent's trust that the world exists with dependable social orders, is significantly challenged. When an individual death, random, absurd and meaningless in every way is experienced as part of God's plan, solace is found (Klass, 1988). A bereaved parent therefore frequently turns to something or someone outside of themselves in which to seek explanations and find answers for their tragic loss. The use of religious interpretations and rituals at a time such as death prevents the bereaved from giving way to fear and horror, which could result in their disintegration (Klass, 1988). It is perhaps in the context of death and dying that the meaning of the word religion, which is derived from the Latin *religare*, meaning 'to bind', is most explicitly revealed.

2.3.3 Talking about death and expressing grief

Some societies see death as taboo and discussions of it are regarded as morbid. Worden (1982) however indicates that affective expression of grief is important to the grief process. Adequate resolution of grief may not be accomplished when it is not permissible to verbalise one's experience of grief (Johnson-Moore & Phillips, 1994). Being able to express and

discuss feelings about death allows grievers to not feel alone in their grief and gives them the comfort of shared responsibility and shared grieving (Kubler-Ross, 1969). Therefore it combats feelings of loneliness. Furthermore if there is secrecy amongst family members about death and dying issues, preparatory grief is hindered when there is terminal illness and (as outlined previously) the end result of death is felt to be much more dramatic (Kubler-Ross, 1969).

Literature on the many different ways that caregivers might choose to cope with the death of a loved one is vast. In sum however the most commonly used coping strategies amongst parents who face the death of their children are hope and denial. Furthermore parents frequently turn to their religious beliefs to find meaning in their loss, which assists their grief process. Literature on coping with death additionally highlights that expressions of grief are important but in societies where death is regarded as a taboo bereaved individual's find their grief silenced and this serves to obstruct grief resolution. Secrecy and silence therefore do not facilitate healthy coping with loss.

2.4 Support networks

The most consistent finding of research on grief is that social support is central to the quality of its resolution (Klass, 1988). Bereaved parents share with all grievers the need of an empathic and supportive community. Parents need to express feelings in order to understand and then resolve the emotions which accompany the death of a child. It is therefore important that there is a supportive context in which bereaved parents can share their feelings (Klass, 1988). Grief is a normal response to loss but it is difficult to cope with if there is a lack of support. Often the support of large extended families maintains a bereaved person through their grief process (Dudley, 1992). However parents who have lost children to AIDS repeatedly find their social support inadequate and this exacerbates their feelings of isolation and loneliness (World Health Organisation, 2002).

When an individual experiences an AIDS-related loss others may fail to recognise or support that person's grief reaction due to the stigma associated with the disease. Potential support providers may hold negative feelings, such as fear, toward the bereaved person. Moreover, especially in communities with high rates of AIDS deaths, sources of support may be severely limited or nonexistent. Community support may be depleted by widespread infection

as this may result in social networks such as friends or neighbours having little energy to support one another owing to the likelihood that their own families are struggling with the impacts of AIDS-related deaths (Ingram, Jones & Smith, 2001).

The substantial physical, emotional, financial and time demands created by AIDS caregiving means that those who assume primary responsibility for it struggle to cope with everything on their own (Saengtienchai & Knodel, 2001). A common response of caregivers is to solicit help from others within their family. However the stigmatised nature of AIDS often reinforces the tendency of parental caregivers to limit their call for help to only within their immediate family thus experiencing limited social support (Ingram, Jones & Smith, 2001).

Furthermore the stigma associated with AIDS means that caregivers are susceptible to receive unsupportive social reactions. These are distressing responses that an individual receives from other people concerning their loss (Ingram, Jones & Smith, 2001). These reactions may include discouraging statements or expressions of feelings about the loss, minimizing the impact of the loss or making rude or insensitive remarks about the loss. Ingram, Jones & Smith (2001) stated that unsupportive social reactions during bereavement are annoying, disappointing and upsetting to a bereaved individual. Unsupportive social interactions are associated with increased depression in bereavement and have an overall detrimental psychological functioning among people who have suffered a loss (Ingram, Jones & Smith, 2001). Positive social support in contrast has been identified to promote better psychological well-being of bereaved individuals as it mediates distress as opposed to evoking it (Ingram, Jones & Smith, 2001).

2.5 Grandparental foster care

Following the death of an adult child most African older mothers unavoidably face the long-term responsibility of providing foster care to their orphaned grandchildren. In sub-Saharan Africa more than five million grandparents are estimated to be taking care of several orphaned grandchildren (Paul, 2002). This is one of the impacts of the AIDS epidemic on older persons that has received the most attention in the mass media. These grandchildren are commonly referred to as "AIDS orphans" (Saengtienchai & Knodel, 2001). The United Nations Children Fund (UNICEF) defined these orphans as children, who below the age of fifteen, have lost their mother to AIDS and have lost or will lose their fathers to AIDS

(UNICEF, 1999). Thus defined UNICEF estimated that AIDS in Africa would orphan 13 million children by the end of 2001 (UNICEF, 1999). AIDS has orphaned more children in Africa than anywhere else (UNICEF, 1999). The AIDS crisis in Africa primarily devastates the traditional caretakers of children, their biological parents, resulting in an increased reliance on other family members to take over the caretaker role (Anderson, 1994). The extended family network however has become overburdened due to the growing numbers of AIDS orphans. To date research has revealed that the majority of AIDS orphans are being absorbed into the extended family system and few incidences of alternative foster care arrangements have been witnessed, although the large number of children needing care is overwhelming this system (Foster & Shakespeare, 1995; Ntozi, 1997; Rutayuga, 1992).

2.5.1 Importance of family foster care

Bowlby (1967) described the absolute importance of attachment between a child and a loving caretaker. His guiding principle was that the right place for a child is in his or her own home (Anderson, 1994). Bowlby advised that if a loving parent could not raise a child, the psychologically sensible course of action would be to identify a meaningful relative in the broader family group with whom the child could share an attachment and relationship (Anderson, 1994). The reliance on extended family members, frequently observed within African families is therefore consistent with Bowlby's recommendation to respect attachment within the family. Research studies have found that it is commonly agreed that children orphaned by AIDS are best cared for within their extended family and grandparents are the first choice of caregiver (Paul, 2002; Rutayuga, 1992). Despite the emotional value of this arrangement for the orphaned children the long-term impacts on grandparents is significant (Mupedziswa, 1997).

2.5.2 Impacts of grandparental foster care

Grandparents struggle to look after grandchildren as there are many emotional, social and material needs associated with raising children. Grandparents with limited resources struggle to meet these needs. Nyanguru (1991) observed that much of the real impact of AIDS-related deaths affect surviving grandmothers the most, who are required to provide long-term care to their grandchildren (Mupedziswa, 1997). Grandmothers are typically stranded with young grandchildren when their adult children die, as there is a perceived obligation for

grandmothers to look after them (Cross, 2001). Increasingly other family relatives are becoming less forthcoming to offer care to AIDS orphans owing to the many burdens associated with their foster care. Therefore grandmothers are often the only available and willing members to assume this role, which they do with little support from other relatives (Cross, 2001). Children need schooling, medication from time to time, counselling and discipline but above all they need food, clothing and shelter (Mupedziswa, 1997). The added expense of caring for grandchildren adds noticeably to a grandmother's struggle to sustain her family (Cross, 2001). In most cases grandmothers are challenged to meeting the needs of their grandchildren especially after losing essential contributions from their adult children (Sankar, Luborsky, Rwabuhemba & Songwathana, 1998).

Assuming full-time parenting responsibilities for grandchildren is associated with increased psychological distress which is most often manifested in symptoms of depression (Kelley, Whitley, Sipe & Yorker, 2000). Grandmothers experience the role shift from grandmother to new mother as stressful as it involves unanticipated changes in all aspects of their lives. Feelings of anger and resentment commonly are felt as a result of having to assume unexpected and unwanted roles (Kelley, Whitley, Sipe & Yorker, 2000). Furthermore there is a range of additional factors which have been identified as contributing to increased psychological distress in grandparental caregiving (Kelley, Whitley, Sipe & Yorker, 2000). Some of the most frequently documented factors include poor physical health, social isolation and financial difficulties. Financial difficulties are regularly identified as the primary source of severe stress in poor households affected by HIV/AIDS (Cross, 2001). The combination of additional dependency (orphans) and income loss (adult children's deaths) plunges many families into severe poverty (Cross, 2001). Less documented factors which contribute to psychological distress, include: circumstances involving the onset of care, changes in role demands, conflict with grandchildren and their potential behaviour problems (Kelley, Whitley, Sipe & Yorker, 2000). The events that lead to care of grandchildren can be highly distressing, such as in the case of a long and difficult period of HIV/AIDS caregiving followed by the death of an adult child. Grandparents often express feelings of shame, guilt and anxiety due to their children's AIDS death (Kelley, Whitley, Sipe & Yorker, 2000). Furthermore grandmothers frequently face the news that their grandchildren are HIV positive. Mother-to-child transmission of HIV is one of the major causes of HIV infection of children in Africa (Preble, 1990). When grandmothers inherit their orphaned grandchildren it is common that within a short duration of time one or more grandchild will become ill and are

later diagnosed HIV positive. This adds significantly to a grandmother's distress in the months following the death of her own child. This aspect of caregiving is rarely addressed in the literature despite of the tremendous psychological strain caused by witnessing the loss of one's own child and grandchild. Experiencing multiple losses can result in bereavement overload (Carmack, 1992 cited in Anderson, 1994), which occurs when there is overwhelming grief precipitated by the occurrence of multiple losses with little allowance for separate grieving time. It has been reported that the pain suffered by grandparents whilst caregiving orphaned grandchildren is heightened by the lack of hope for their grandchildren's future (World Health Organisation, 2002). This loss of hope accompanies the realisation that it is likely that their ill grandchildren will die before reaching young adulthood. Grandparental foster care is therefore a significant additional source of psychological distress suffered by older women in their role as caregiver to their families struck by HIV/AIDS.

2.6 Motivation for the research and the research hypothesis

Despite numerous older women in South Africa compelled to act as caregivers to their adult children with AIDS and their orphaned grandchildren, thus far research has not addressed sufficiently the psychological impacts of the caregiver role on these women. The needs of older people remain undifferentiated in HIV/AIDS awareness campaigns and strategies that are aimed at alleviating the household level burden of HIV/AIDS. The appalling scale of the impact of HIV/AIDS on the poor in South Africa has been acknowledged in research (Cross, 2001), however the psychological impacts, which are suffered by older women who sustain these households remains underreported. In response to this identified gap in research this study aims to explore the lived experience of older African women in Grahamstown in the Eastern Cape Province of South Africa whose lives have been impacted due to their HIV/AIDS-related losses. Particular emphasis is placed on the psychological implications of the death of their adult children and the role shifts involved in fostering orphaned grandchildren without adequate support and with limited resources.

The research hypothesis is as follows:

- Older African women continue to respond to their family's care needs. This response stems from their belief that the extended family is a system of shared support should exemplify their cultural philosophy of *ubuntu*.

- However older women find themselves abandoned in their caregiving roles and suffer significant ongoing psychological distress due to the impacts of this role on their emotional and physical well-being.

CHAPTER THREE

METHODOLOGY

3.1 Aim of the study

This study focused on the experiences of older mothers who acted as parental caregivers to their adult children with AIDS. After the death of their children the mothers inherited the long-term responsibility of providing care to their orphaned grandchildren. For the purpose of this study parental caregiving therefore included the period of caring for an adult children with AIDS and the subsequent long-term care of orphaned grandchildren. The study looked systematically at the various aspects of parental caregiving and the responses given by the older women to this role. Six questions were focused on:

- (1) Why do older mothers become caregivers to their sick children?
- (2) What is the experience of being a caregiver to an adult child with AIDS?
- (3) What is the experience of losing an adult child from AIDS?
- (4) What coping strategies do older mothers employ to facilitate their capacity to cope with the loss of their child?
- (5) What sources of support are available to older mothers during caregiving and after the death of their child?
- (6) What is the experience of fostering orphaned grandchildren?

3.2 Sample

The sample selection was purposive, i.e. the purposive sampling method involves sampling according to pre-determined characteristics. This allows for information-rich cases to be selected specific for the purpose of the research (Patton, 1990). Three older African mothers who were also grandmothers were selected for this study, based on the following criteria:

- They were 50 years or more in age. This cut-off age was based on recent research done by the World Health Organisation that used this benchmark age to describe an *older person*. Their research selected this age after discussions relating to chronological, cultural and functional categorizations of people as “old”. It was noted

that especially in African contexts one is commonly categorized as “ageing” at the age of 50. Two reasons were given for this (1) people who live in developing countries in poor conditions experience many burdens and therefore they generally age prematurely and (2) in most African traditions the title “older person” is socially dictated by one’s role in society for example becoming a grandparent confers such a title (World Health Organisation, 2002).

- They had cared for an adult child infected with AIDS who had returned home during the final stages of their illness.
- Their adult child had subsequently died of AIDS.
- They were responsible for fostering orphaned grandchildren some of whom were HIV positive.

The researcher approached the Grahamstown Hospice for access to a sample group who would meet the abovementioned criteria. Hospice is a non-profit organisation, which offers holistic (physical, emotional, social and spiritual) home-based care to patients with active incurable illness specifically Cancer, AIDS and other end stage illnesses. Their care includes family support both during a family members illness and the period of subsequent bereavement. The Grahamstown Hospice Administrator was informed about the nature of the study and the proposed method of conducting the research. The Administrator signed a consent form which outlined the academic nature of the research and what the research would entail namely that interviews would be conducted in the participants’ homes and that their involvement in the project would be confidential and voluntary. The Grahamstown Hospice community workers agreed to meet with women who were on their patient lists and who met the sample criteria. The purpose of their meeting was to provide the women with information about the project and to ask if they wished to participate. The women who agreed were asked to sign a consent form compiled by Hospice acknowledging that they had been informed about the nature of the project, that their participation was entirely voluntary and that Hospice had permission to give their names to the researcher. They were informed that the research would be conducted in their homes and that a Xhosa speaking translator would accompany the researcher.

The following are descriptive characteristics of the three women who were selected for the research sample. (Refer to Appendix One for a more complete description of the women)

- The participants were all Xhosa speaking, married and live in the informal settlements within Grahamstown. Their household compositions ranged between six and eleven members. The participants were financially supporting their households with their old age pensions or disability grants. One of the participants received financial assistance from her husband's old age pension.
- The period of caregiving for their adult children with AIDS ranged between five to nine months.
- The death of their children ranged between three to six months prior to their involvement in the research.

3.3 Data collection

The data was collected using a series of semi-structured interviews, focussing on the six research questions. Semi-structured interviews consist of a sequence of themes as well as suggested questions which serve as a guide for the researcher. The semi-structured nature of the interviews allows a researcher to maintain an openness to change in sequence and forms of questions whilst using the guide. This facilitates the follow up of any interviewee responses (Kvale, 1996). An advantage of this interview style is that it enables the researcher to study complex experiences, with the participants being able to qualify or explain their answers. It also allows for the expression of ambivalent or contradictory feelings which contributes to the rich nature of the interview material (Barker, Pistrang & Elliot, 1994). The use of semi-structured interviews in this study therefore enabled the researcher to obtain qualitative descriptions of parental caregiving with the emphasis on the participants' lived experience and meaning.

3.4 Creating the semi-structured interviews

As outlined in 3.3 the semi-structured interviews made use of an interview guide. The researcher compiled the interview guide accordingly; first the researcher entered a process of

brainstorming and freely considering the issues which would be important to explore in relation to the research questions. This brainstorming process was influenced to a degree by the literature which the researcher had read prior to embarking on the research. Second the ideas generated from the brainstorming process were grouped together according to the themes of the six research questions. The interview guide thus consisted of a list of questions that were to be discussed over the course of the interviews. The research guide assisted in delineating the broad areas of investigation and helped to ensure that essentially the same information was obtained from all three participants.

Each participant was interviewed three times for between two to three hours. Meeting three times enabled the researcher to:

- Pursue topics which had emerged spontaneously during an interview but which had gone unexplored due to the time limits of that interview
- Revisit topics in order to clarify statements and details noted in previous interviews

Therefore interviewing the participants over a series of three interviews enabled the researcher to observe the topic under study to great depth.

The interviews were conducted in Xhosa with the assistance of an English / Xhosa translator. The interviews were audiotaped and transcribed verbatim by the researcher. The transcriptions of the nine interviews served as texts, which the researcher analysed.

3.5 Data analysis

This study used a grounded hermeneutic approach to research the topic of exploration. Although the researcher relied heavily on the methodological approach of grounded theory in the data analysis it was not possible to employ a pure grounded theory methodology as the researcher had conducted extensive reading on the topic of study prior to the analysis of the data, which thereby influenced the analysis and the categories derived from the data. Therefore a more fitting description of the research methodology is grounded hermeneutic theory, as hermeneutic methodology emphasises the important influence of the researcher (in this case the researcher's prior reading) on the act of interpreting research data (Patton, 1990).

This having been said the methodological proceedings of the study were significantly influenced by the theoretical underpinnings of grounded theory, as it was valued for its inductive strategy of generating and confirming theory that emerges from close involvement and direct contact with the experiential world (Patton, 1990). In this vein research findings are grounded in a specific context, and the theories which result from the findings are grounded in real world patterns (Patton, 1990). As the focus of this research was on the lived experience of older mothers acting as parental caregivers it was considered valuable to utilise a methodological approach which holds as its focus the individual and the empirical world.

Methodological procedures specific to grounded theory analysis, namely coding, constant comparison, theoretical memo-ing and integrative diagramming (Van Vlaenderen, 1999) were utilized in the analytical procedure in order to inquire into the research topic under investigation.

3.6 Analytical procedure

Firstly the researcher read through the data gathered from the nine interviews which served as texts. This initial phase was open and consisted simply of reading through the texts. The data was then re-read with the accompaniment of a reading guide. The reading guide specified the six focal areas of the research and guided the researcher's examination of the data accordingly. This entailed the researcher combing through the data and identifying indicators, which are facts, behavioural acts or events embodied in the texts (Van Vlaenderen, 1999) that were associated in meaning to the six categories outlined in the reading guide. The indicators were then separated into the six categories. They were then coded which entailed grouping the indicators together according to shared meaning. These groups of indicators were then examined further with the aim of selecting code names that would best describe the shared meaning or theme encapsulated within the clusters of indicators. After the data was sorted thus far the researcher entered a process of refining the codes. That is, the researcher re-read and re-examined the codes, being alert to the possibility of having to move indicators to different codes, exploring whether a code could be sub-divided and possibly having to alter a code name to improve its descriptive value of the indicators it encompassed. In this phase of analysis the researcher was careful to note any new themes that might have emerged in the process of refining the codes. Once these analytical phases were complete the researcher was able to draw integrative diagrams of the data. These diagrams involved presenting the data in

a diagram format which facilitated elucidating the relationships between the codes which had emerged in the analysis.

Concurrent to completing these analytical phases the researcher made use of the constant comparison technique used within the grounded theory methodology. This method calls the researcher to constantly question whether there are gaps, omissions or inconsistencies in the data (Van Vlaenderen, 1999). The researcher made notes of these in the form of theoretical memos that were later used to inform the analytical and interpretive procedure. During the data analysis the process of constant comparison also acted as a measure which enhanced validity and reliability.

3.7 Ethical considerations

For the purpose of this study the following ethical considerations were adhered to:

3.7.1 Information and consent forms

Research participants signed a consent form which provided an accurate description of the aims and nature of the study. The consent form stated that participation in the study was voluntary and confidential.

3.7.2 Privacy, anonymity and confidentiality of data

Although the participants' names were known, these did not appear anywhere in the research. As outlined in the consent forms, which the participants signed, no identifying information was included anywhere in the research. Research participants were asked to sign a standard departmental permission form for the interviews to be audiotaped. This form stated that the audiotapes would be destroyed after they were used for transcription purposes. Interview transcripts were coded using alphabetic letters so that the participant's names did not appear. Owing to the secrecy associated with HIV/AIDS the women were asked if it would be permissible to conduct the research in their homes. This was discussed prior to the start of the research so as to ensure that the home visits would not compromise the participants in any way. Additionally the participants were informed before hand that a translator would accompany the researcher and that she would be bound by the same confidentiality

commitments as the researcher. It was explained that the translator was a qualified nurse who occasionally did locum work for the Grahamstown Hospice. It was emphasised that for the duration of the research the translator would not be working at Hospice and that no interactions with Hospice staff would occur while the participants were involved in the project. This was emphasised so as to allow the participants to feel permitted and safe to share their feelings about Hospice support if this arose during the interviews.

CHAPTER FOUR

RESULTS

The research results are presented according to the categories outlined by the research questions. Diagrams are used to represent the findings.

4.1 Routes to parental caregiving

The participants became primary caregivers for two reasons. These are depicted in Figure 1 and are discussed below.

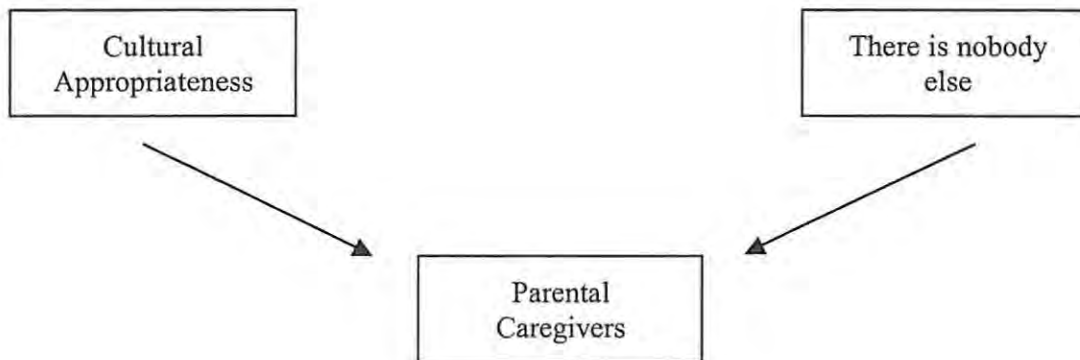


Figure 1: Causal factors to becoming a parental caregiver

4.1.1 Cultural appropriateness

The participants perceived parental caregiving to be culturally appropriate. This cultural value was reflected in the participants' belief that providing care to their children was their parental responsibility. This sense of parental responsibility was a powerful influence in their decision to act as parental caregivers. The caregiving arrangements for both the sick adult children and the orphaned grandchildren were linked with the prevailing cultural norm that women act as caregivers in the family.

The following quotations reflect the above finding:

“Most of them (adult children), they do come back home when they are sick. Maybe it’s because they want to be cared for by their parents because there is no other person who can look after a child except a parent. When somebody is sick they must be cared for. There are expectations to care and it is usually the mothers.” (K)*

“It was difficult to care but the point is that I am not going to share this burden with somebody else because it is mine. I had to carry this load of burden because I am the person in the household who is always carrying all the burdens, nobody else.” (N)

4.1.2 There is nobody else

The participants’ adult children had been living elsewhere when they became sick. By the time their illness had progressed they were living unaccompanied and unaided. This was either because a spouse had already died of AIDS or because a partner had deserted the relationship when their partner showed signs of AIDS infection. The adult children were forced to return home during the end stages of their illness as they had considerable caregiving needs which they no longer could perform for themselves. Owing to the fact that there was nobody else to help their adult children the participants felt compelled to assume this caregiving role.

“I took it like he had to come back home because he was alone. There was nobody to look after him so he decided to come back home.” (N)

“She was all by herself and her child. When I went over to her where she stayed when I heard that she was sick, I could see that there was nobody looking after her, nobody to cook for her, nobody to wash her, nobody doing anything for her. She asked me if she could come home and I couldn’t chase her away. She told me that she wasn’t going to stay anywhere else because she wanted to stay here. I had no choice.” (M)

Note: * The participants names have been coded using alphabetic letters so as to ensure their anonymity and confidentiality throughout the study.

4.2 Responses to the caregiving role

The participants' responses to the caregiver role are outlined in Figure 2 and discussed below.

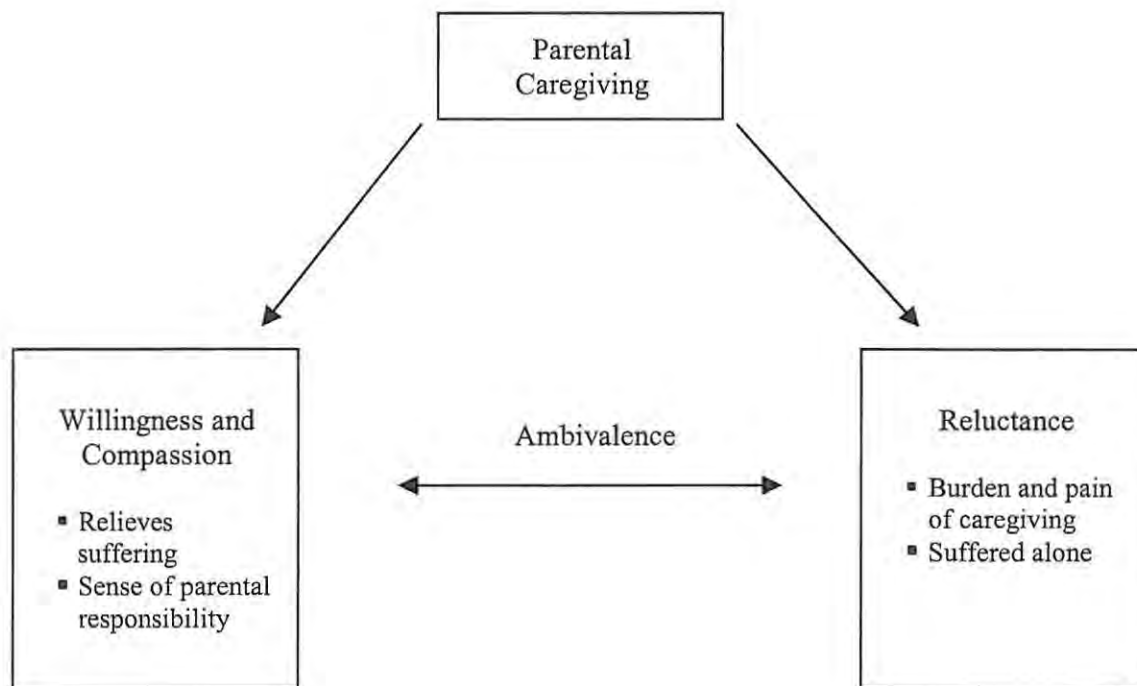


Figure 2: Response to parental caregiving

The children's homecoming was met with ambivalence. On the one hand the mothers felt willing to care for their children and compassionate towards their needs. Their willingness was motivated by their desire to relieve their children of suffering which they perceived was their parental responsibility. On the other hand caregiving was believed to be accompanied by many burdens and emotional pain which caused the participants to resist this responsibility. Compounding their resistance was the knowledge that other family members would not be forthcoming with support. However the participants' sense of responsibility outweighed their reluctance and they assumed the primary caregiving role to their children until their children's deaths.

4.3 Parental caregiving

The participants desired to demonstrate unconditional love to their children. They did not however experience caregiving as an easy task. The strains and burdens of their responsibilities meant that the role was experienced as exhausting. They experienced physical and emotional exhaustion. These are discussed respectively.

4.3.1 Physical exhaustion

Three factors resulted in the caregivers' experience of physical exhaustion. These are depicted in Figure 3 and presented below.

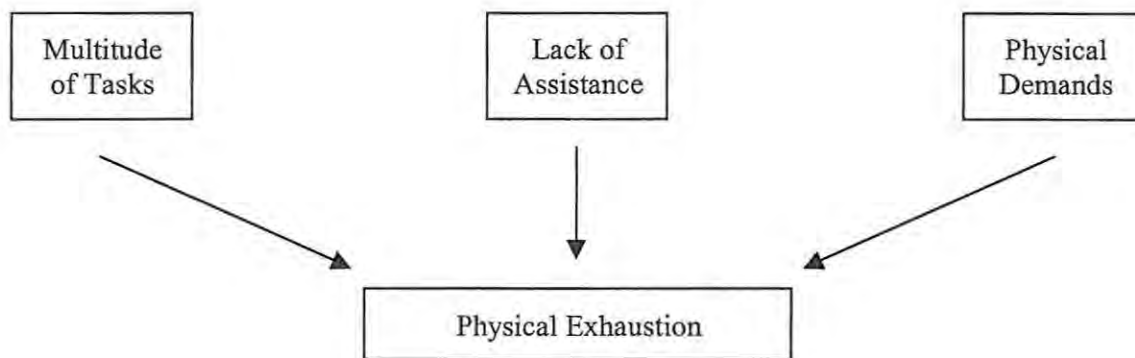


Figure 3: Factors which contribute to physical exhaustion

4.3.1.1 Multitude of tasks

The caregivers were required to assist their children with all the tasks of daily living and health care. These were considerable since the children had returned home at the terminal stage of their illness when their health had severely deteriorated. The caregiving tasks included preparing special food, feeding, washing, accompanying their children to the toilet and monitoring their health by dispensing the correct medication throughout the day and assisting with fever management. The extensive nature of the home-based care evoked a sense of exhaustion amongst the caregivers.

“I had to crush her tablets for her, everything I made I had to be sure that she would be able to swallow it, I even cleaned her mouth because she had sores in her mouth.

When she came over here she couldn't swallow. I used to give her bed baths. I would do the dressings and after I have done all of that in the morning I would feed her porridge." (M)

4.3.1.2 Lack of assistance

The considerable needs of their children meant that the caregivers had very little free time to themselves as they were entirely occupied with the care of their children. Caregiving without support meant the burdens of caregiving were not shared and the caregivers were not relieved of their responsibilities. This resulted in feelings of tiredness. Compounding their tiredness was the fact that most of their nights were disrupted with caregiving tasks.

"It was a very difficult time caring for her because I couldn't go anywhere I had to be in the house all the time. I also felt I didn't want to leave and go and visit anywhere because I didn't want her to feel neglected I wanted her to feel like I still loved her." (K)

4.3.1.3 Physical demands

The participants experienced some of the caregiving tasks as particularly physically demanding. Caregiving involved frequent lifting, supporting and moving their sick children and this tired the caregivers. These activities heightened the participants' sense of being old and frail against the heavy weight of their sick children.

"There were times when I thought I am too tired and I would think no I will attend to those chores at another stage I am tired now, the body can't take it anymore. My body when I would go to bed at night, it was so painful that I always asked myself will I be able to get up tomorrow?" (N)

4.3.2 Emotional exhaustion

Various aspects of caregiving evoked a range of negative psychological states. These states were expressed as different feelings, which the participants experienced in combination throughout their caregiving. The range of negative emotions felt over the course of caregiving contributed to the participants' overall experience of emotional exhaustion. Figure 4 depicts the range of feelings associated with emotional exhaustion and are presented below.

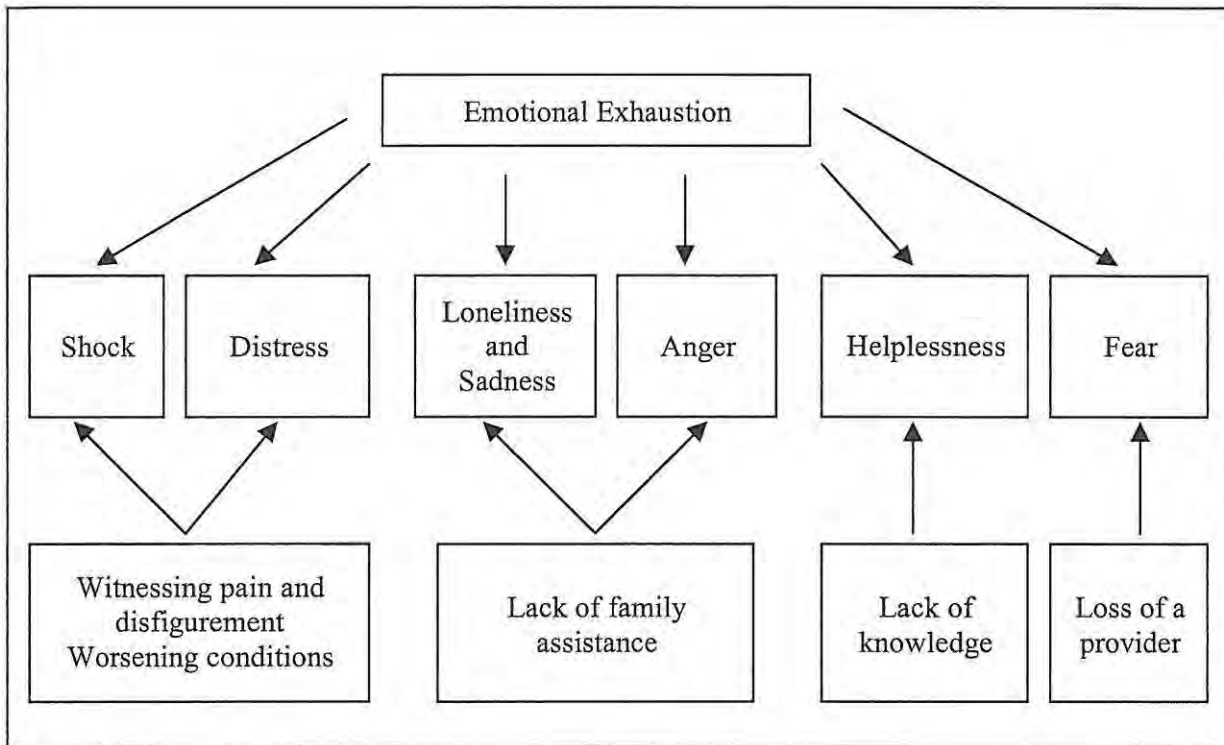


Figure 4: Participants' experience of emotional exhaustion

4.3.2.1 Shock

The participants described feeling shocked when their children returned home. The progression of their illness had withered the children to such an extent that one woman described not being able to recognise her child when she entered the house.

“I was very much shocked when she arrived home because of the way she had changed I even doubted when she came through the gate that it was her. It was very painful. I was so shocked for a long time, looking at her in her condition I was just standing and staring at her until she begged me to sit down and she said it was her.”
(K)

4.3.2.2 Distress

Excruciating pain, progressive physical deterioration and wasting away characterised the participants' children's conditions. Witnessing the children's worsening conditions served to evoke significant distress for the caregivers.

“I could see him losing weight and going down in health. He couldn’t walk, he couldn’t do anything for himself and then we had to take him to hospital. It was very painful. It was a difficult time for me.” (N)

“She was in so much pain it was intolerable. At times I would not stay with her even after giving her medication I used to go out because I couldn’t stand seeing her in so much pain. I would go and sit outside. It was so painful and some times the Sister would come and she would find me sitting outside and I would tell the Sister that I couldn’t stand to see this child in so much pain. There were times when I would say Lord please take this child into your hands so that at least she will be better.” (M)

4.3.2.3 Loneliness and sadness

During the months of caregiving the participants felt alone. The primary source of loneliness was the fact that other family members did not offered support during the months of caregiving. The participants felt that family support would have significantly alleviated the strain of caregiving. It was concluded with sadness that family members seldom show care for one another. Family support was perceived as an old traditional custom no longer practiced amongst families. The participants believed that the extended family network was once a valuable source of support.

“It’s no longer there the extended family support, the extended families seem to be running away when the situation of sickness is there. That has definitely changed from the old days, the extended family support.” (M)

“It’s no longer happening that word ubuntu; it is no longer there in our people they just leave you with your own problems. People used to look after each other in the olden days it was not like this. Is it not because people they no longer love and care for each other?” (N)

4.3.2.4 Anger

The added burden of having a sick person in the family meant that the participants’ responsibilities increased in the home. They described feeling overburdened and unsupported during their caregiving. They expressed anger at having to bear the caregiving burdens of their children and children’s children without the support of other family members. The lack of family support therefore contributed to both the experience of loneliness, sadness and anger.

“I used to have a grudge for the family when I was caring for my child. I used to think to myself where is the rest of the family why can't they come forward and help me. I used to feel angry, asking myself, why am I alone with this?” (K)

“They were not supportive while I was caring for her and they don't support me now...nobody came around when I was caring for her. I tried to explain to them that they must come.” (M)

4.3.2.5 Helplessness

The participants described feeling helpless as a result of not knowing the cause of their children's illness.

“We took him to hospital not knowing what was wrong with him. We gave him medicine all the while not knowing what was wrong with him. He couldn't walk, he couldn't do anything for himself and so we took him to hospital. I never knew anything.” (N)

4.3.2.6 Fear

The participants experienced fear when they discovered that their children were dying of AIDS. Their children's deaths represented the loss of their chief supporters and household providers. The pending death of their children thus served to undermine the participants' experience of future security which their adult children's lives had assured.

“My thoughts when I heard that she was sick were now what am I going to do because I was depending on her in everything and her children were depending on her, what am I going to do?” (K)

“My thoughts were oh she's got this sickness she is going to die. I was heart sore. I was very worried because I thought my helper is going to leave me.” (K)

The overarching experience of caregiving was therefore that of exhaustion. Both physical and emotional exhaustion was experienced as a result of many features associated with caring for an adult child with AIDS. When the participants reflected on their caregiving experiences they felt as though it had accelerated their ageing.

“I feel tired and sick now, it is one of the reasons why when I look at myself I feel I have aged very quickly.” (K)

4.3.3 Stigma associated with HIV/AIDS

The caregivers faced challenges owing to the fact that their children had AIDS. These challenges related to the stigma associated with HIV/AIDS and manifested in various forms of AIDS-related discrimination. This served to cause additional distress during caregiving. The stigma associated with HIV/AIDS was related to two factors namely; fear of infection and shame.

4.3.3.1 Fear of infection

The participants noticed that very few family members visited their homes during the months that their children were home. They identified fear of infection as being the cause for their families' absence. The participants noted that fear of infection is uniquely associated with HIV/AIDS because there is no cure for the disease. Fear of contamination therefore caused of the participants to experience feelings of alienation and limited support whilst caregiving.

4.3.3.2 Shame

The participants' believed that the community viewed AIDS as a shameful disease. This shame was associated with (1) being dirty (2) being sexually promiscuous (3) being unfaithful to one's partner. The participants' identified a belief within the community that AIDS is considered a punishment for people who behave irresponsibly and in shame. The participants felt that because of the shame associated with HIV/AIDS people avoid being associated with the infected and their families. Furthermore the participants additionally experienced occasional hostility from friends and family members due to the shame of being associated with HIV/AIDS infected individuals. One participant explained that a family member had expressed rage that her infected child was being cared for within the family, as the relative had feared the implications for the family of being associated with a person living with AIDS.

“With the first child that died my relatives used to come and visit when I was looking after her, that is the one with cancer. Amazingly with this one nobody came around when I was caring for her. Is it not because they are afraid of this thing? That's what I thought about it, people are afraid of this sickness. People say they are afraid because this sickness is infection. I think they were thinking bad thoughts about her because

she had this sickness, that is why they didn't want to visit. I think they thought she was a bad girl. I still wonder inside of me, why didn't they come? I have got an elder sister in law she stays just a few blocks from here but she never came here. When I asked her why she didn't come and visit this child she said no she can't come and be infected with HIV/AIDS. She came straight to me and she told me straight to my face that she would never come to my house because I am keeping somebody who has this dirty disease and it is infectious and she will never come here. I was so angry with her to say such a thing" (M)

"When you have got something like this AIDS people start swearing at you, belittling you because you have got this kind of thing, they start talking nasty about you and your family. When somebody knows or hears or suspects that your children have died of HIV, they start making a mockery of you"(N)

4.4 Losing an adult child to AIDS

The participants' grief reaction consisted of a range of emotions which occurred over the course of their grief. These are depicted in Figure 5 and presented below.

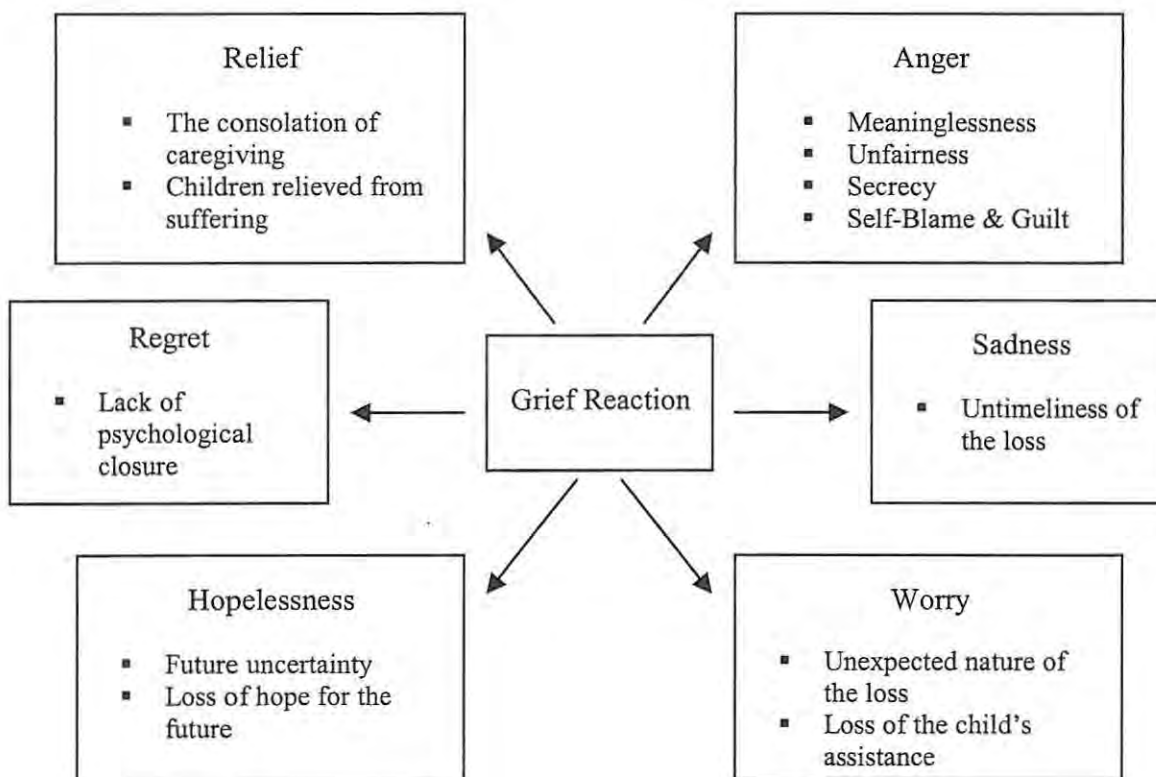


Figure 5: Participants' grief reaction

4.4.1 Anger

A number of factors contributed to the participants' experience of anger. These are outlined below.

4.4.1.1 Meaninglessness

The participants struggled to find meaning in their loss and this evoked anger. They turned to God for in search of meaning. They tried to understand their loss by wondering if God was punishing them or if God was calling them to be better Christians. These two explanations however did not satisfy the participants or relieve their anger.

"I feel very sore and I ask God why did it have to happen, why did this happen to me? There are times when I want to confront God and ask Him what have I done wrong? I want to ask God to please take away these memories because I can see this is going to shorten my life." (N)

"I am still wondering why this happened like this, maybe God wants me to come nearer to him and pray more to Him. Maybe then He will make me understand. I always ask God why did you do this to me why did I have to suffer?" (K)

4.4.1.2 Unfairness

The participants felt angry that their children had died in the most productive years of their lives. They compared their children to other healthy young adults living in the community and felt angry at the unfairness of their loss.

"I look at them, the healthy ones, and I think they are also like my child and they are strong and there is nothing wrong with them there is no sickness in them." (K)

4.4.1.3 Secrecy

The participants also expressed anger at their children for concealing their HIV/AIDS status from them. It angered them that despite enduring the emotional and physical stress of caregiving their children did not chose to confide in them. They surmised that the reason for their children's silence was because of the belief amongst young people that AIDS should remain a secret. They disapproved of the secrecy around HIV/AIDS because they saw it as

the reason why the disease was spreading and that it prevented caregivers having access to information about their children's conditions, which they believed served to deny them the opportunity to seek suitable assistance for their children whilst providing care. The participants believed that when a person's sickness is concealed necessary help-seeking behaviour cannot take place which in turn hastens that person's death. For these reasons the children's secrecy was a source of great anger amongst the participants.

"You know the people who counsel us they tell us we must always be prepared for this sickness and this thing of taking it and keeping it inside of you that's the thing that is going to make you worse. You must talk about, that's what the counselling people always tell us. Why didn't she tell me? As a parent I feel I am supposed to know what she was sick with, I don't know why they keep on hiding behind the other sicknesses. They would never tell and not to tell your parent it's even worse than what is wrong with you" (M)

"That's the worst pain about it because nobody told me what was wrong with my son. If he would have told me that he had this sickness as people say it makes you better, I always feel that if he had told me what was wrong with him I would have made plans for him to live longer. But what discouraged me is that he never ever told me what was wrong with him. If I had known I would have gone to certain places. He didn't give me the chance to do that it would have been better. It makes me cross." (N)

4.4.1.4 Self-blame and Guilt

The participants' additionally expressed anger towards themselves. This was reflected in their emotional reactions: self-blame and guilt. Two factors evoked these responses. They expressed guilt at having not taken their children into their homes sooner and provided care earlier on in their illness. They also regretted having not spoken to their children about the cause of their illness as they felt they could have done more for their children had they known what was wrong. Despite feeling angry with their children for their secrecy the participants blamed themselves for not having encouraged their children to confide in them. The participants believed that if they had cared for their children earlier and been more active in seeking help they might have prolonged their children's lives. Their self-blame and guilt were therefore associated with having not effectively prolonged their children's lives.

"I felt ashamed of myself when I saw my child so sick. I always say to myself oh Lord I wish I would have taken her in earlier than I did and stopped making excuses like I am also sick and I am too old so I can't take you. I feel if I had taken her much earlier than I did maybe she would have lived longer." (M)

4.4.2 Sadness

The participants' experienced profound sadness after their loss. Their sadness stemmed from their ruminations over their belief that children should not die before their parents. The untimeliness of the participants' losses was a source of great sadness.

"My greatest sadness is that I never expected a child to die before me because I always had that hope that she would be the one who would bury me but it is not going to happen. This is one of the things that I think of, that I was hoping that I would be buried by my child...not me burying my child. I trusted her that she would look after my other children and my house and the family when I am not here. This is not at all what I expected I never expected it. It was too soon for me. That is the hardest part when I think what I have lost." (K)

"It is a painful thought when I think about it that he was supposed to be looking after me when I am old and sick but now he's gone. I had to look after him. It's a painful thought that I have. It is still painful knowing that he will never come back. I still think about it that he would have been the one who would be doing the job of caring for me." (N)

4.4.3 Worry

Additionally the untimely nature of the participants' children's deaths served to evoke worry for the participants. They had expected their children to care for them in their old age and they had depended on their children's support. The participants realised that with the death of their primary supporters their future needs were going to be left unmet and this was a source of great worry as it undermined their future security.

"Children are supposed to look after their parents when they become old and sick. There are lots of things that you expect from your children." (N)

"It is supposed to be that we leave them and not they leave us. We are being left alone, nobody to support us." (M)

"She was the breadwinner for me she used to do everything for me. She supported me, she bought groceries and she bought building materials and all this furniture. It's very hard to lose children, it's worse when they are grown up and they have been doing things in the family." (K)

4.4.4 Hopelessness

The participants' adult children had represented hope for their futures. With their children's deaths the participants experienced an overriding feeling of hopelessness.

"I have no hope of what is going to happen to me, what can I hope for now? I don't know maybe I will die tomorrow." (M)

4.4.5 Regret

Two factors served to evoke feelings of regret amongst the participants after their children's deaths. First having not said good-bye and second having not spoken to their children about death. The participants explained that to talk with their children about death would have been unacceptable. It was not considered unusual practice within their culture. Talking about death to a terminally ill person was perceived to be dabbling with witchcraft and a bad omen. They also feared that such talk would hasten their child's death. Talking about death before a person has died was also believed to contradict the responsibility of a caregiver to maintain hope until the end of a person's life. However in their grief the participants expressed regret at having not chosen to speak to their children about dying or taken the opportunity to say good-bye. On reflection the participants concluded that talking about death would have prepared them better for their children's death. They believed that it would have given them a feeling of peace when faced with having to let their children go.

"I couldn't prepare myself at all. That is why I say it was a very short time. I would have prepared myself you know by talking with him having time to speak to him so that I could also prepare myself that I know this sickness in the end he is going to die but I didn't have that chance. To me it seems like this would have made a difference. I would have liked to have said to him you were my helper in my life, but I can see now you are on your way out, good-bye." (N)

"We don't allow one to talk to a dying person about death. Our belief is that if we talk about death before he dies we will speed his process of death. We are losing out because we don't talk about such things when a person is sick. With our culture people will say it's a very bad omen or you are bewitching the person, they will start pointing at you and saying you have witchcraft in you. In our culture it is not done, it is not acceptable. We can never prepare ourselves for death, nothing it's really hard. If I was allowed to talk in such a way I would have loved to talk to him because now as I sit here and I know nothing." (M)

4.4.6 Relief

The participants felt relieved and consoled by the fact that they had acted as caregivers to their children until their children's deaths. Caregiving had given them the opportunity to fulfil their role as mother to its completion. To the participants this was a valuable consolation. Despite the hardship that parental caregiving had incurred it did offer the participants a sense of satisfaction.

"I have looked after him that was my consolation. It is just that satisfaction that he died in my arms." (N)

"I am glad that I was able to look after her until the last days of her life." (K)

"The only thing that I think I gave her during the last days was love and care and I made her aware that I loved and cared for her this is my consolation." (K)

4.5 Caregivers' coping strategies

The participants displayed two prominent means of coping during caregiving and bereavement. During caregiving the participants utilised hope as their primary means of coping while in their bereavement they relied on their belief in God as a coping strategy. Figure 6 represents these coping strategies and they are presented below.

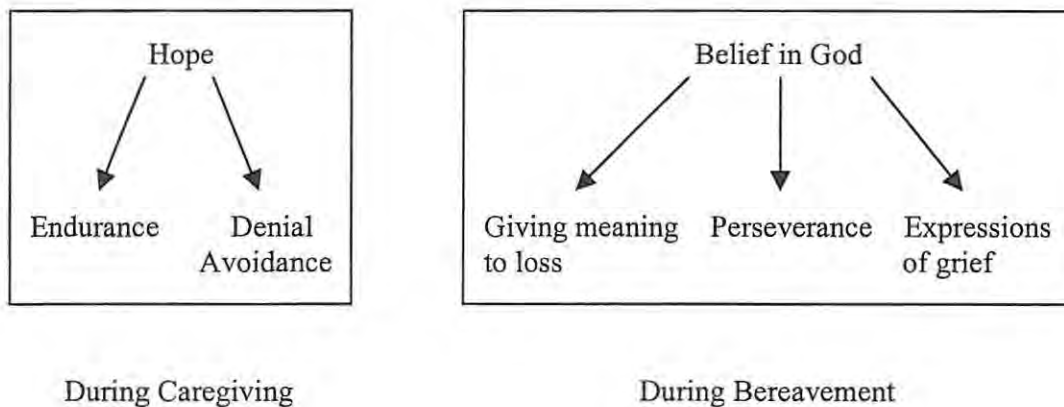


Figure 6: Coping strategies

4.5.1 Hope

During caregiving the participants' primary mode of coping was to maintain hope. Despite their adult children's fast deteriorating health the caregivers continued to hope that their children would eventually become well again. Signs of improvement in their children's conditions, for example when there were slight symptomatic improvements such as being able to swallow again or move and lift themselves with less need for assistance, served to sustain the participants' hope. Although these improvements were transitory they encouraged the participants who maintain their hope throughout the period of caregiving. Therefore hope served to facilitate the endurance of witnessing the gradual degradation of their children's health.

"I always had that hope that he would be better and still be with me. I never stopped having hope." (N)

"I had that hope when she came over to me that she would get better." (K)

However their hope additionally served as a means of avoiding and denying the reality that their children were in fact growing weaker, that their symptoms were progressing and that their deaths were inevitable. Despite these facts the participants believed that having hope was an essential part of caring for a sick person and that accepting death before a person has died was inappropriate as it undermined their hope.

"We don't allow one to talk to a dying person about death. Our belief is that if we talk about death before he dies we will speed his process of death. With our culture people will say it's a very bad omen or you are bewitching the person, they will start pointing at you and saying you have witchcraft in you. In our culture it is not done, it is not acceptable." (N)

"It is very difficult, while the person is sick you are busy talking about death and yet you've got that hope that this person is going to be well. Even the very person who is sick always has hope that they are going to get better. I used to tell her not to talk about death all the time because that will shorten her life" (K)

4.5.2 Belief in God

The participants' used their belief in God as their primary coping strategy during their bereavement. Their belief in God facilitated coping in three ways.

- It facilitated giving meaning to their loss

This was achieved by being able to make sense of their loss in the context of believing that God has a greater plan for one's life. The participants' acceptance of this principle allowed them to understand their losses as part of God's plan. They also believed that God had saved their children from suffering and this was a source of relief. Their ability to make sense of their loss within the context of their religion therefore brought them comfort.

"I believe God has taken her because I always believe that there will come a time when God will take his person and if He doesn't want to take you He will not because it is not your time yet." (M)

"It is so heart sore that God has taken her at such a very young age but at the same time I feel He has done her good because when I saw her suffering with lots of pain I would rather she go than see her suffering. God has done His own will" (K)

"I do have that belief that he is resting in the arms of our Creator, he is at peace. This comforts me." (N)

- It facilitated perseverance

The participants trusted in God and had faith that He would continue to provide for them in the future and would instil in them strength to carry their burdens. This allowed the participants to face the long-term consequences of their losses with perseverance.

"I always trust God that my future is in His hands everything that I do is in God's hands so will be my future...I am solely depending on that." (K)

"I always thrust that the Lord has given me these burdens and He will help me to carry them." (N)

- Prayer and gospel singing facilitated expressions of grief

The participants prayed and sang whenever they felt overburdened with worry, when they mourned their losses with sadness, when they felt afraid and in need of help and when they felt weakened by their burdens. The religious practices of prayer and song provided the caregivers with a context in which to express their distress, which they acknowledged went

largely unspoken. Their songs revealed that they perceived God as their protector and their friend and their refuge.

“Whenever I pray I always pray to be able to carry all the responsibilities and the burdens which I carry in this family.” (N)

“I just kneel and pray when I am worried and I ask God to take away the worries. I pray when I have problems and I ask God to give me strength to get through things and to come through my problems. I just sing and pray on these days, the days when the burdens feel heavy.” (M)

4.6 Support offered to caregivers

The participants received both emotional and material support from various sources. Figure 7 outlines this support according to the different time periods during which it was received.

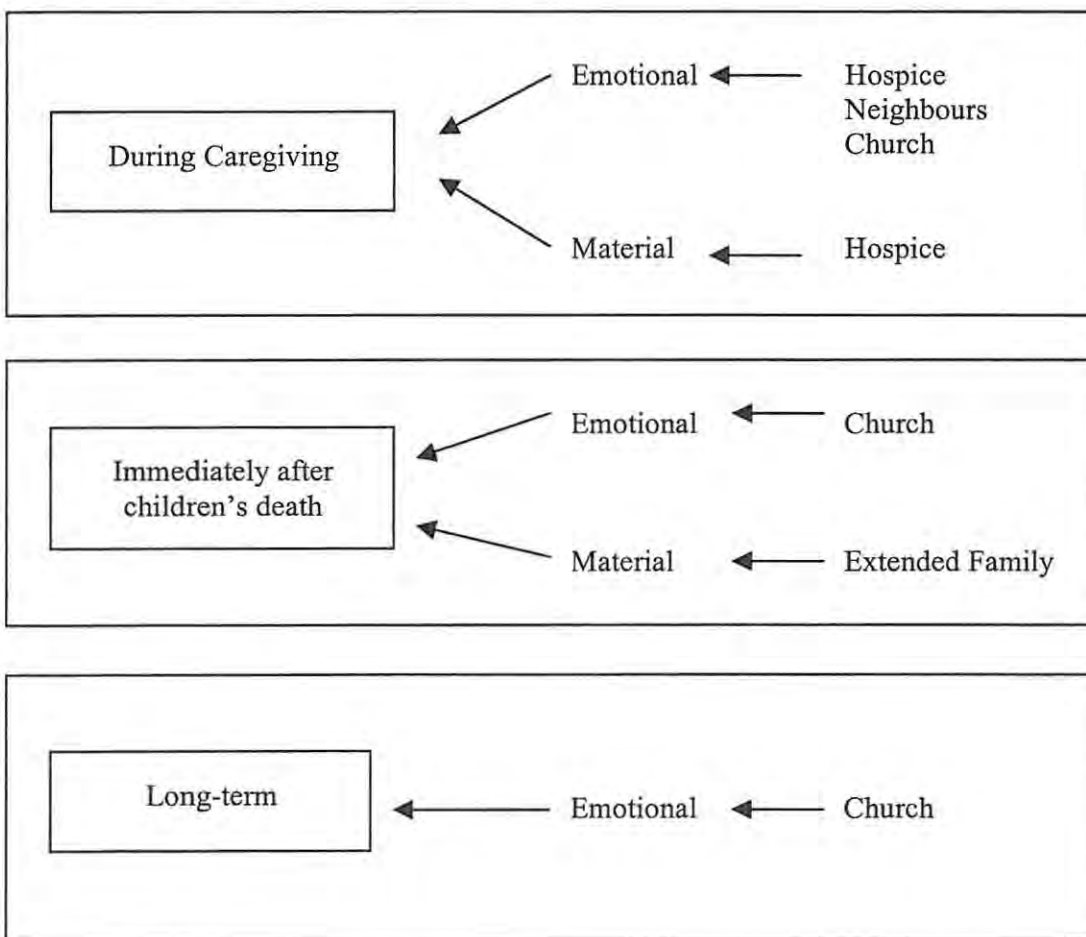


Figure 7: Nature and sources of support according to three time periods

4.6.1 During caregiving

The caregivers received both emotional and material support during the time that they were caregiving. The sources of support were hospice, neighbours and church. These are discussed below.

4.6.1.1 Hospice

When their adult children returned home in advanced stages of AIDS illness the participants were comforted by the support they received from the local hospice. This support came in the form of material aids to assist with caregiving tasks such as dressings for the wounds, bed sheets, gloves etc. and information on caregiving practices. They also received emotional support from the hospice staff during their home visits. Hospice was an important source of support to the women while they were caring for their children.

4.6.1.2 Neighbours

Neighbours who visited the caregivers offered prayers and sympathy to their families. The emotional support they received from friends comforted the women and alleviated their experience of isolation.

4.6.1.3 Church

The caregivers attended women prayer groups, which they identified as being a significant source of comfort and help during the months of caregiving.

4.6.2 Immediately after children's death

Caregivers received emotional support at this time from their church and material support from their families. The most significant source of support at this stage was the material support the participants' received from their families. These sources of support are outlined below.

4.6.2.1 Church

Church group members attended the funerals and offered emotional support to the caregivers immediately after the death of their children.

4.6.2.2 Family

The extended families offered material support on the day of the funeral. The main commodity offered was food. The caregivers were grateful for these contributions as it offered financial relief during the weeks immediately after the funeral.

4.6.3 Long-term

The participants' only source of long-term support was received via their churches in the form of emotional support. They received ongoing emotional support months after the their children's deaths. This is outlined below.

4.6.3.1 Church

The participants met at their churches daily. They attended prayer groups during the week and church services on the weekend. The church represented an emotional support network which the women relied heavily upon. They received emotional support from their churches throughout the course of their caregiving and were continuing to access support at the time of the research. Their churches were active in the community and the women spoke highly of the quality of support they received from their fellow churchgoers. Visiting and praying with church members provided the women with a context in which they felt permitted to share their burdens and feel supported. This support network was active in the women's lives from before their children became sick and was therefore a familiar and trusted source of support.

“I just go to church. It consoles my sole and I feel good after going to church.” (K)

“I do go to church and I have also got a prayer band where we always pray together. In this prayer band it is where we share problems with each other. Each one of us tells their problems and then afterwards everybody has had a chance of telling their problems and then we have a chance to pray about all we have spoken about. This prayer band has got great support, you know when I go there maybe feeling down

when I come out of the band I always feel good. The role that the prayer band plays in our lives is really great.” (M)

4.7 Responses to orphaned grandchildren

The participants described how traditionally grandparents are expected to provide care to grandchildren when their parents are working, sick or deceased. This was considered their grandparental responsibility. As with the cultural appropriateness of providing care to their adult children it was considered culturally appropriate for the grandmothers to function as primary caretakers to their grandchildren. The route to parental caregiving was echoed in the route to grandparental foster care. Grandmothers were identified as loving guardians of grandchildren and their homes were considered the best place for orphaned children to be raised.

“Grannies take more care of the grandchildren than anyone in the family.” (K)

“As far as I am concerned grandmothers should look after the grandchildren. Grandmothers have that feeling, that extra mile for their grandchildren and how to look after them.” (M)

The grandmothers had been fostering their grandchildren for some time before their adult children became ill. This had occurred for two reasons (1) the children’s parents had separated, their mothers worked full-time and their fathers was not involved with any parental responsibilities or (2) the children’s mother had died of AIDS and their father was not able to take care of his children and work full-time. Therefore when the adult children returned home during the end stages of their AIDS illness the participants simply continued to provide care for their grandchildren. The significant difference however was the fact that now the grandmothers were expected to foster their grandchildren without the financial and material support they had been receiving from their adult children when they were well. Subsequently the participants displayed mixed reactions to inheriting full responsibility for their orphaned grandchildren, as they feared the implications of fulfilling this duty without the necessary support.

“There is a big difference now that she is gone there is nobody to help me.” (N)

The participants' responses to caring for their grandchildren are depicted in Figure 8 and outlined below.

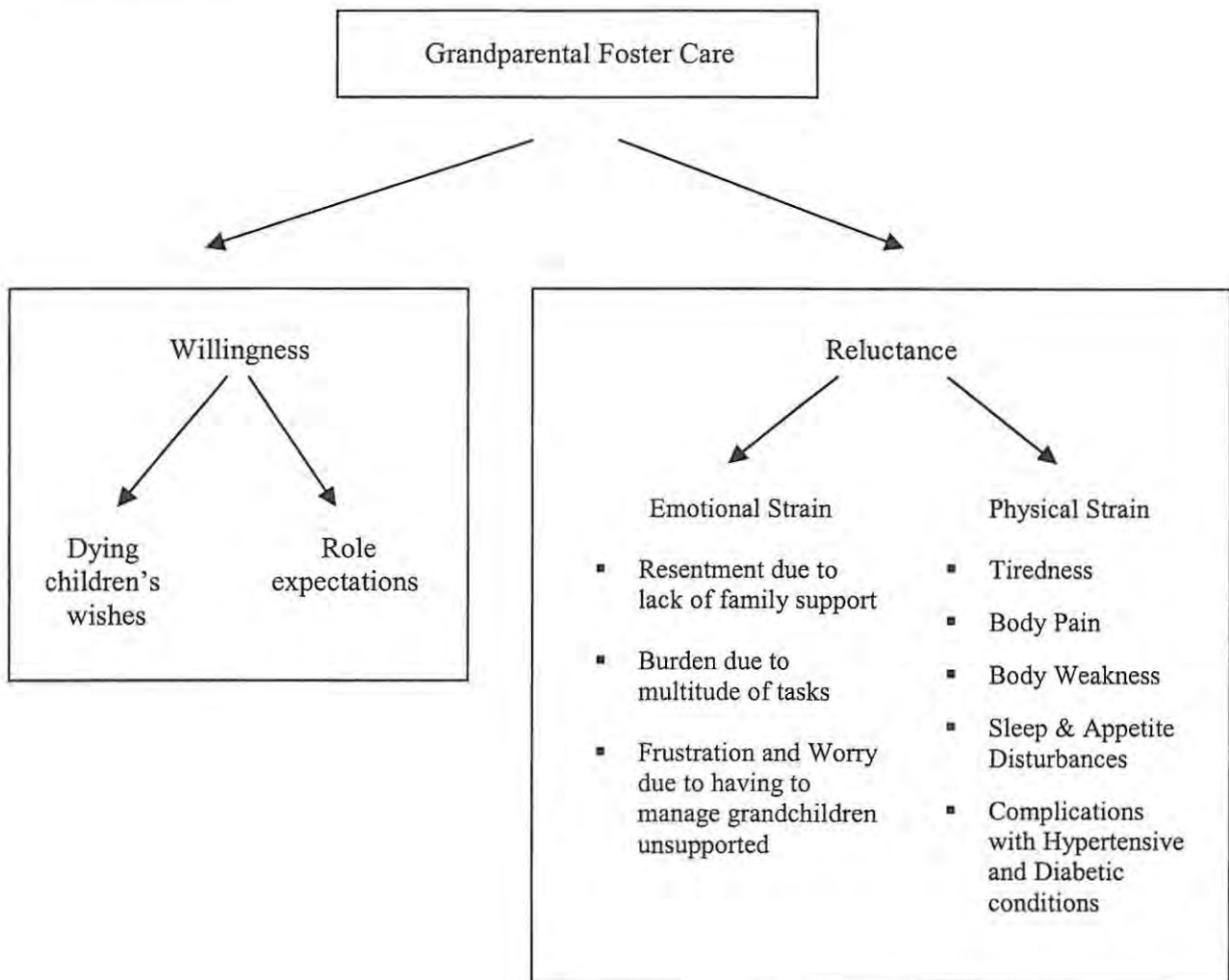


Figure 8: Participants responses to foster care

4.7.1 Willingness

Factors, which evoked willingness to care for orphaned grandchildren, were associated with:

- being able to fulfil the wish of their dying adult child who requested that they foster their children
- fulfilling the expectation to provide care to all family members, thereby fulfilling their cultural duty to care for family members.

“I enjoy looking after my grandchildren being a mother again. A grandmother and a mother are the same person; to me looking after my grandchildren is a real joy.” (N)

“My responsibility as a grandmother, which is my wish, is to look after my grandchildren as I used to look after my own children.” (K)

“I accepted the responsibility of looking after this child because my daughter asked me before she died to look after her child.” (M)

4.7.2 Reluctance

In contrast however there were noticeably more reluctant responses to foster care. The participants’ reluctance stemmed from emotional and physical strain associated with foster care responsibilities to orphaned grandchildren. This is outlined in the following sections.

4.7.2.1 Emotional strain

Emotional strain resulted from a range of negative emotional states. These are described below.

- Resentment

The absence of extended family support during the months that followed the participants’ children’s deaths served as a chief source of resent amongst the participants. The participants felt abandoned by their families and trapped with the long-term responsibilities of fostering their grandchildren, which evoked much resentment. This was exacerbated by the occasional critical response which the participants received from relatives regarding the manner in which they were raising the grandchildren. Conflict within the extended family over the grandchildren and the resentment which the caregivers felt toward being stranded, contributed significantly to the caregivers’ emotional distress.

“In the first place if my daughter were alive she would be staying in her own house with her own children. Now she is gone leaving me with this burden of this child. I always say if she would be alive I wouldn’t have this burden of this grandchild. I wouldn’t have had the responsibility if her mother had not died...I didn’t have any worries in the beginning because I thought it wouldn’t be a difficult task to look after this child. Now it is not like that, it is difficult now. I did not expect it to be like this. Firstly this child, I don’t get any support of any kind and I am not working. The family is starting to blame me for so many petty things. The extended family they

were not there when I was looking after her mother on my own but now they are starting so criticise me saying I am doing this and that. It is worse because even at school now there are so many things that the school want, there are things like shoes and all that and now they start blaming me, the relatives, saying things like look at her she is shabby, she hasn't got shoes, she hasn't got this and that and I don't work...I don't know where they think I must get something to buy shoes with. I feel angry when I hear what they are saying about me" (M)

- Burden

The participants felt burdened with the long-term responsibility to care for their grandchildren without support. Resuming the role of 'mother' left them feeling weighed down by the demanding tasks involved in the foster care of young children. The children's caregiving needs included washing clothes, preparing food, supervising school work, keeping an eye on their whereabouts and in general being available to them all the time.

"It was very difficult for me because now I have to be a mother again, starting from phase one and it's a difficult thing. I am responsible for everything in the household like when the children come home from school I must make something for them to eat. I look after each and every member of the family. That is my responsibility. It is a big responsibility." (K)

"There are no differences between a mother and a grandmother. Grannies educate the grandchildren in the family, that is just one of their roles. If you are a granny there are so many things I don't even know where to start to tell you. I am a mother again because I cook and I do washing for them. It is full time to look after them. I have a big responsibility. Grannies are like mothers and their responsibilities are even worse when somebody is sick in the family. The role of the grandmother becomes greater. There will come a time when grandparents can't look after more children. It's worse because we are growing old as we live. There are times when you feel the burden is too much." (N)

- Frustration

The participants found disciplining grandchildren particularly frustrating. Often the grandmothers experienced their grandchildren resisting or ignoring their attempts to discipline them. The participants believed that their grandchildren's resistance to being disciplined was because of the significant age gap between them. Furthermore they felt that a grandmother's role in the family traditionally was to spoil grandchildren and not to discipline them. The role shifts thus involved in becoming full-time mothers again caused resistance amongst the children and frustration amongst the grandmothers.

“Really it’s not easy. It’s becoming worse as we get older because these children they don’t listen to us, they are naughty. You will say to a child stop doing that and they will think you are joking because you are a granny. It makes me angry this.” (M)

“It’s not easy disciplining them really. It gives me stress.” (K)

- Worry

Worry was identified as a significant source of emotional strain. The participants’ worry involved three factors.

(1) The grandmothers worried about the fact that they were old and would not likely live long enough to care for their young grandchildren until the age at which they could care for themselves. They worried about who would take care of their grandchildren after they died.

“There’s a lot of things to worry about. I think of the children...what will I do with this big responsibility of these children? It’s a lot of children. It is a heavy burden. It’s very difficult for me...it’s making me worry a lot having to raise these children” (N)

“You know this is too much for me the worry of the grandchildren. This is one of the problems that keeps me awake at night and I can’t sleep, as it is now I am on the verge of giving up I don’t know where to go now. I am growing too old.” (M)

(2) The grandchildren who were HIV positive needed specific care and the grandmothers doubted that they would have enough energy in the future to repeat caring for a person with AIDS. An additional source of strain associated with this was the fact the participants believed that their grandchildren were too young to be informed about their HIV status and therefore decided to keep their condition a secret. However the participants felt wearied by the burden of keeping their family’s secrets. Furthermore the participants believed that the clinic nurses and hospital doctors had given them, as guardians of the HIV positive children, the responsibility to keep the children’s HIV status a secret which they felt burdened them as caregivers.

“That’s my main worry the future. When I look at the little one I am very concerned and worried about her future. I think to myself will I be there for her when she gets worse, how will my health be when she gets sick like her mother, will I be able to look after her as I have looked after her mother? These are my concerns about her

future because she is also infected. The sickness is the same, as her mother's and I don't know how will I do it." (M)

"I must keep this one's sickness a secret because even at the clinic they tell the person responsible for the child that no other person but you the person responsible for the child must know. That is why I will keep it a secret. I felt because they only told me, it will remain a secret...I am keeping it a secret because I was told it is a secret." (N)

(3) Future financial insecurity was another source of worry. Without the support of their adult children the grandmothers persistently felt worried that there was not have enough money for everybody in the household. This worry was accompanied by degrees of frustration at not being able to meet their grandchildren's needs. Despite engaging in informal income-generating activities the grandmothers still struggled to afford the household's cost of living. The added expenses of food, clothes, school fees and other costs associated with raising children added noticeably to the families' financial hardship.

"My worries are sometimes that they want lunch and they haven't got, they want money and they haven't got, they have no lunch box to take to school. It worries me a lot. This is a worry this money, this worries me because everything today you need money for, there is nothing you can do without money. I am so worried when I see that the money won't be enough. I am not coping at all." (K)

"I must be careful with the money now. Money is the problem because when I think about it is not enough for all the needs that we have in the household. My heart is so sore because if this money gets finished now and I know the groceries are going to be finished before the month end and then I don't know what I am going to do. It is my responsibility to see that the money lasts. I worry very much, alot of worries. It is so difficult when this money doesn't go to all that I want. I just feel like sleeping even if it's daytime. It makes me feel tired, exhausted because there is no one else that is going to help me sort out this financial problem." (N)

4.7.2.2 Physical strain

The physical strain, which the participants' experienced whilst providing foster care to their grandchildren, manifested in a range of physical complaints. These were: feeling constantly tired, having body weakness and body pain, experiencing disturbances in sleep and appetite patterns and suffering from complications with their hypertension and diabetic conditions which they had suffered from for many years but which they felt worsened due to the stress involved in caring for their grandchildren.

“I do feel very tired and I have body pains are all over my body. I have never noticed this weakness before or these headaches and tiredness it is only now. My sleep is disturbed because I think a lot about my child and my grandchildren. I also have a loss of appetite mostly because I will find at times that without even eating my stomach is full and I don’t want to eat I don’t know why. It’s a new thing for me this” (K)

“I’m diabetic and I have high blood pressure and I take treatment for those things regularly but there are times even though I take the treatment that I will feel my body is sick even if I have taken the treatment.” (M)

“There are days when I don’t feel like doing anything anymore but I must just do it. I feel like this because I am growing old and I don’t feel well. I have sleepless nights. It has never been a continuous sleep for me. It has been there for a long time that I don’t sleep right through the night. I wake up in the night. I just lie there and think about all my problems, there are a lot of things to worry about.” (N)

CHAPTER FIVE

DISCUSSION

In this chapter the results outlined in chapter four are interpreted and discussed in relation to similarities and differences found between this study and the works of others. This chapter discusses the results divided into two categories, namely during caregiving and during bereavement. In the first section the results which are discussed are those associated with how the participants came to be caregivers and their experiences of this role. The second section explores the participants' grief reaction to their loss and their responses to the inheritance of orphaned grandchildren. In both sections the participants' coping strategies and access to support are included in the discussion.

5.1 During caregiving

How the participants came to be caregivers and their experience of this role are discussed in the following sections, in addition with a commentary on the participants' coping strategies and the nature of support available to them during this time.

5.1.1 Routes to parental caregiving

The participants of this study became caregivers to their adult children for two reasons. First they considered it to be their parental duty. This duty was underpinned by the cultural expectation amongst African families that women traditionally act as caregivers in the family. The caregiving arrangements that emerged in this study were therefore linked to the prevailing cultural norms regarding gender roles. The predominance of women in caregiving positions in families is a common phenomenon observed in most societies (Cross, 2001; Saengtienchai & Knodel, 2001; World Health Organization, 2000, 2002). In particular, within the African family system the role of mother comes with family-wide obligations primarily associated with caring for children and grandchildren (Cattell, 1997). The participants' loyalty to their culturally defined role, which compelled them to provide care, outweighed their reluctance to this duty. Their reluctance was associated with the burdensome and painful nature of providing care to a child with AIDS unsupported. Research conducted amongst older African caregivers in Botswana found that older women continue to provide care to

their children living with AIDS despite the compromise it had on their emotional and physical health. This was a result of a shared cultural expectation amongst their families that women provide care within their families even in old age (World Health Organisation, 2000).

Second, the participants acted as caregivers to their adult children because they felt compelled to as no other family members were willing or available. The traditional function of the African extended family to provide shared social support to all its members (Cattell, 1997) was not evident in the research findings. Rather the participants experienced being abandoned by their relatives. In practical everyday terms it was evident that the elderly – in particular elderly women – sustained their family's capacity to provide care unsupported. This finding was consistent to that of Mupedziswa (1997) who observed that in Africa fewer and fewer family relations are willing to become involved in providing care to sick family members due to the unprecedented number of HIV/AIDS infected individuals and the tremendous strain they have on the family system. The participants noted that family relationships had changed from the traditional family system where family members were far more involved in actively supporting each other. They regarded the younger generation as no longer placing value in the importance of shared support within the family unit. Cattell (1997) identified that within African families many young adults travel to find work, they leave home soon after finishing school and visit less and less and increasingly fail to fulfil their traditional duty to care for their older and younger relatives.

5.1.2 Experience of caregiving

In their role as caregivers the participants suffered physical and emotional strains that were associated with the overriding feelings of physical and emotional exhaustion. Physical exhaustion was caused by the multitude of tasks involved in HIV/AIDS caregiving, the physically demanding nature of some of the caregiving activities and the time consuming nature of this role. HIV/AIDS caregiving has been identified as particularly arduous, and parental caregivers are vulnerable to feeling overwhelmed (Paul, 2002).

Emotional exhaustion on the other hand occurred as a result of a range of negative psychological states which served to drain the participants emotionally. Shock and distress, caused by witnessing their children's ongoing pain and suffering, severely traumatised the participants during their time of caregiving and contributed to their overall feeling of

exhaustion. Peabody (1986) has emphasised a similar finding. Loneliness, sadness and anger caused by the lack of family assistance during the months of caregiving further contributed to the participants' emotional exhaustion. These feelings arose during caregiving despite the fact that the participants received emotional and material support from hospice, neighbours and church groups. The participants experienced a pervasive sense of abandonment throughout their time of caregiving as a result of their unmet need for family support. Other research has noted that changes in African family structures due to the stressors of poverty, HIV/AIDS and increasing family migration negatively effects Africa's elderly as they are left abandoned and unsupported by their families (Cattell, 1997). The participants identified that the shame associated with HIV/AIDS and the widespread fear of infection, accounted for their families' lack of support. They found that their association with their sick children caused alienation from their families and was the reason for occasionally hostile and unsupportive responses from their relatives. Leary & Schreindorfer (1998) noted that being associated with a stigmatised person is in itself cause for being stigmatised. Research has noted that the AIDS crisis, which has far reaching effects on family unity, threatens to deplete the traditional interfamilial and intergenerational support characteristic of the African extended family network (Ankrah, 1993; Catell, 1997; McDonnell, Abell, & Miller, 1991; Ntozi, 1997; Rutayuga, 1992; UNAIDS, 1999; World Health Organisation, 2002).

Further contributing to the participants' emotional exhaustion during caregiving was the feeling of helplessness. This was evoked by the participants' lack of knowledge associated with their children's condition. They attributed their lack of knowledge to their children's secrecy and the silence of the doctors and nurses. However the research results highlighted that in fact the participants themselves played a chief role in being rendered helpless whilst caregiving. This was revealed in the results which indicated a contradiction between the participants' accurate knowledge of the symptoms of HIV/AIDS and their claims that they could not identify the cause of their children's illness. In addition having not received a formal diagnosis from either a doctor or nurse the participants chose to deny their local knowledge of what a person looks like who is suffering from HIV/AIDS and adopted an attitude of: we were not told and therefore we did not know. The research findings therefore identified that the children's, doctors' and nurses' secrecy was a source of passivity amongst the caregivers as it perpetuated ignorance and limited the caregivers' active search for information which in fact rendered them helpless. Other research has noted that community health care workers are concerned about the effect of secrecy around HIV/AIDS on families,

as they increasingly observe that it exacerbates a silence around the disease (World Health Organization, 2000), which in turn interferes with information-seeking behaviour. The research findings further identified that during caregiving the participants' passivity and denial were in fact an extension of a deeply embedded cultural manner of coping with death. This was believed to account for the participants' lack of awareness of the link between not accessing knowledge and furthermore denying knowledge about something and the feelings of helplessness this creates.

Finally fear emerged as another source of emotional upheaval for the participants during caregiving. Their fear was in response to the threat of losing their family's primary supporter. This fear was exacerbated by the fact that the caregivers had not expected to care for their children's children. Parental caregiving represented complete role reversals within the family system. Elderly family members within the African family typically rely on their sons and daughters to care for them in their old age and not vice versa (Paul, 2002).

As mentioned previously the participants' way of coping during caregiving was highlighted in the research results as a factor which exacerbated their emotional exhaustion. The participants' primary mode of coping during caregiving was to maintain hope. However the participants' hope served to uphold their overall denial of the severity of their children's illness and the inevitability of their deaths. Although it has been recognised that hope is an important feature of parental caregiving (Saengtienchai & Knodel, 2001) if it, as highlighted in this research, is prolonged it facilitates an entrenched denial of death. Again denial has been identified as an important feature of allowing parents to cope with the pending death of a child (Kubler-Ross, 1969) however, if maintained it is regarded as an obstacle to grief resolution. If hope for a child's recovery is maintained throughout the period of caregiving and denial of death is upheld, parents ultimately disrupt their process of anticipatory grief (Dane, 1991). The anticipatory grief process is valuable because it provides time for a parent to prepare for the death of their child and thus the final impact of death is reduced. Without preparation for death, as in the case of sudden deaths, grief is likely to be prolonged and complicated and the bereavement state becomes difficult to resolve (Sanders, 1989). In this research the participants' hope and denial prevented them from adequately preparing for their children's death. Dane (1991) identified that parents who are faced with a child's AIDS diagnosis and the anticipation of their death typically respond to the news with shock or an inability to understand or accept it or they deny the reality of it. The findings of this study

highlighted similar parental responses as represented by their hope and denial. Sustaining hope and denial throughout a period of caregiving in the face of a terminally ill person's suffering and severe physical deterioration was considered in this study to be a significant contributor to feelings of emotional exhaustion.

5.2 During bereavement

The participants' grief reaction, their way of coping with death, the role of support in their grief and their responses to their orphaned grandchildren are discussed below.

5.2.1 Participants' grief reaction

The participants' grief reaction included feelings of anger, sadness, worry, hopelessness, regret and relief. Factors associated with their dependency needs on their children, their inability to use the time during caregiving to prepare themselves for their losses and the social stigma associated with their children's AIDS-related deaths proved to intensify and complicate the participants' grief reaction. Parental grief is regarded as one of the most difficult grief processes to resolve, and it is not unusual for parents to experience complicated grief particularly if the deceased is an adult child and their death is socially unspeakable (Dane, 1991; De Vries, Lana & Falck, 1994; Klass, 1988; Worden, 1991).

The research results highlighted that it was difficult for the participants to resolve their grief, as their lives felt completely disrupted with the loss of their adult children. Their anger, sadness, worry and hopelessness were related to feeling unprepared for their children's deaths especially since their adult children were considered the family's chief supporters. Cattell (1997) noted that amongst African families it is customary that middle-aged children support their parents in old age. As found in this research, the death therefore of a middle-aged family member who is the family's most productive member, is a source of significant distress for ageing parents as they subsequently must face sustaining their household unsupported. In all societies the death of a child is always considered untimely and has a profound impact on a parent's sense of future continuity (De Vries, Lana & Falck, 1994; Moss, Leshner & Moss, 1986). The participants regarded surviving their children as a violation of the natural order of family life and this served to complicate their feelings of loss. An inability to accept the death

of a child and a parent's survival-guilt are common obstacles in parental grief resolution (Klass, 1988).

It has been noted however that the act of caregiving to a child in the terminal phase of their illness facilitates parental grief resolution (McGoldrick & Walsh, 1991). This applies if parents utilise their caregiving time to prepare themselves for their children's death, to resolve past conflicts and to express feelings (De Vries, Lana & Falck, 1994). If this is achieved, parents are likely to experience psychological closure after their children's deaths, which facilitates grief resolution (Sanders, 1989). The research results indicated that the participants did not experience a sense of psychological closure in their bereavement owing to the fact that they maintained hope and denial during their time of caregiving. Furthermore the fact that the participants' children had returned home in the end stages of their illness resulted in much of the participants' caregiving time being spent in shock and distress. As a result of these characteristics of the participants' caregiving time the process of anticipatory grief was undermined and psychological closure was impeded. The research results highlighted that in their bereavement the participants' anger, sadness and regret related to the absence of psychological closure. Furthermore the participants' cultural beliefs that talking about death is a bad omen, a sign of witchcraft and an act that hastens a sick persons' death, contributed to the interference of psychological closure and grief resolution. When societies see death as taboo and discussions of it are prohibited, grief is inadequately expressed and difficult to resolve (Johnson-Moore & Phillips, 1994; Worden, 1982).

The secrecy and stigma associated with HIV/AIDS served to perpetuate the participants' silence around their children's deaths and their reluctance to share their feelings of grief. Secrecy amongst family members makes it difficult for any preparatory grief to take place and causes the death to be felt far more intensely during bereavement (Kubler-Ross, 1969). The research findings highlighted that the participants' cultural beliefs about death and the secrecy and stigma around HIV/AIDS resulted in their experience of grief as essentially an extremely lonely process. Silence, secrecy and the experience of loneliness can result in masked or delayed grief, which complicates grief resolution (Klass, 1988; Worden, 1982).

Although the participants did not use their caregiving time to prepare themselves for their losses and were left with the residual sense of lack of psychological closure, they found the act of caregiving to be a source of relief. They felt relieved that they had been with their

children at the time of their deaths and felt that caregiving had symbolised the fulfilment of their role as mother to its completion. They also felt relieved that their children's suffering had ended. The participants' had been deeply distressed and saddened by their children's suffering and in their grief they found relief in the knowledge that their children were no longer suffering so inhumanely.

5.2.2 Participants' way of coping with death

In their grief the participants utilised their belief in God as their strategy for coping. Their religious beliefs facilitated three features of coping which assisted their attempt to achieve grief resolution. First, their belief in God helped them to find meaning in their loss. They believed that their children's deaths were part of God's plan and this brought them comfort. Belief in God and in Divine Providence has been observed to help bereaved parents find meaning in their loss (Klass, 1988). Second, the participants' faith in God helped them to persevere through their bereavement despite their uncertain and burdened futures. Thirdly the activity of praying and singing allowed the participants to express their grief. Being able to express and discuss feelings about death allows bereaved individuals to not feel alone in their grief and gives them the comfort of shared grieving (Kubler-Ross, 1969). In these three ways the participants' belief in God served as a valuable way of coping with their loss. Faith in God has been identified as a significant feature that enables people to cope with negative life events (Klass, 1988). Research in Africa cites religion as the single most utilised form of coping amongst the poor, who have limited resources and few support options. Parental caregivers of children living with AIDS and orphaned grandchildren most often turn to their religion for comfort, support and relief (HelpAge International, 2000; World Health Organization, 2000).

5.2.3 Support during bereavement

The research findings highlighted that the participants' churches were the single source of support to the participants in their bereavement. Visits from friends, family and neighbours were brief, alleviating the participants' suffering only transiently. The most consistent finding of research on grief is that social support is central to the quality of its resolution (Klass, 1988). Grief is a normal response to loss but it is difficult to cope with if there is a lack of support. The extended family is considered the most valuable source of support to bereaved

individuals (Dudley, 1992). The African extended family traditionally represented a large social support network (Cattell, 1997). However increasingly African parents who lose children to AIDS find their social support seriously lacking (World Health Organization 2002). The research results highlighted that the stigma and secrecy associated with HIV/AIDS limited the participants' access to family support. Social isolation, alienation and an inability to express grief because of fear of rejection, have been noted as factors which arise from the stigmatised nature of HIV/AIDS and contribute to the overall experience of isolation amongst caregivers (Dane, 1994). When a loss is socially unspeakable, grief reactions are more likely to be complicated (Worden, 1991). Dane (1994) noted that when grief is kept to oneself because of a stigmatised loss, grievers experience disenfranchised grief, a form of complicated grief which is difficult to resolve. The participants' believed that their lack of family support was largely as a result of the stigma associated with their children's illness. Stigma has been identified to deter family involvement in providing care and support to HIV/AIDS infected individuals and their caregivers (Ingram, Jones & Smith, 2001; McDonnell, Abell & Miller, 1991). Feeling stigmatised evokes many negative reactions from caregivers and is considered to significantly impede grief resolution (Dane, 1994; Ingram, Jones & Smith, 2001).

5.2.4 Responses to grandparental foster care

The participants' long-term responsibility to care for their orphaned grandchildren significantly compounded their grief, in particular adding to feelings of worry and hopelessness. Family expectations were that the participants would continue to care for their grandchildren after their adult children's deaths. As noted by Mupedziswa (1997) the growing responsibility of older parents in sub-Saharan Africa is two fold: the care for dying adult children with AIDS and the foster care of orphaned grandchildren. Today these two responsibilities prove to be an inevitable and inseparable part of African elderly people's lives. In sub-Saharan Africa more than five million grandparents are estimated to be taking care of orphaned grandchildren (Paul, 2002). It is not uncommon for grandmothers to raise grandchildren in African families (Cattell, 1997). Despite the AIDS crisis in Africa and the enormously growing number of AIDS orphans in this region, African families still emphasis the importance of these children being raised within their extended family units (Rutayuga, 1992; UNICEF 1999). However there is growing concern that the African extended family system is fast becoming saturated and will not have the capacity in the future to continue to

support destitute children (Ankrah, 1993; Foster & Shakespeare, 1995; HelpAge International, 2001; Rutayuga, 1992; UNAIDS, 1999).

This study highlighted that the participants' felt willing to care for their grandchildren due to the cultural expectation of them to fulfil this duty, but also experienced reluctance due to the significant emotional and physical strain which accompanied the foster care role. The research results identified that full-time care of grandchildren was associated with a multitude of burdensome tasks, frustration due to discipline problems, resentment due to the lack of family support, overwhelming worry about the future and well-being of HIV positive grandchildren and most of all worry about the financial stress of having to sustain a family with too few resources. Assuming full-time parenting responsibilities for grandchildren has been associated with increased psychological distress amongst grandmothers who find themselves in this role (Kelley, Sipe & Yorker, 2000).

The participants additionally suffered a range of physical complaints during the months that followed their children's deaths. The research results highlighted that these complaints stemmed from the emotional distress which the participants experienced in their role as foster caregivers. They suffered from unremitting tiredness, body pain and body weakness, sleep and appetite disturbances and complications with hypertensive and diabetic conditions.

The long-term burdens associated with foster care responsibilities therefore contributed to the participants' overall emotional and physical strain suffered during their bereavement. Nyanguru (1991) noted that in sub-Saharan Africa much of the real impact of AIDS-related deaths affects surviving grandmothers as they suffer the most in the role shifts involved in providing care to their adult children with AIDS and foster care to their orphaned grandchildren.

CHAPTER SIX

CONCLUSION

The research hypothesis stated that older African women in the Eastern Cape Province of South Africa experience significant psychological distress in their caregiver roles to adult children with AIDS and orphaned grandchildren. The results of this qualitative study substantiated this hypothesis. It was highlighted that both choice and circumstance influence a mother's decision to act as a parental caregiver. Choice as it fulfils what is culturally expected of her and circumstance, as in practical everyday terms she is the only available and willing family member to provide care. However the study highlighted that the caregiver role is associated with a wide range of physical and emotional strain, which serve to render older women emotionally depleted. The lack of sustainable support and the stigma and secrecy associated with HIV/AIDS proves to further exacerbate a caregivers' psychological distress suffered both during caregiving and bereavement. Lack of family support emerged as the primary source of distress and conflict amongst the caregivers. In addition the inheritance of orphaned grandchildren added significantly to the grandmothers' overall psychological distress. The study highlighted that the psychological impacts of HIV/AIDS caregiving do not cease after the death of an adult child but rather are guaranteed to be experienced well into a grandmother's future due to the long-term commitments of independently raising orphaned grandchildren.

6.1 Limitations of the study

The following points are considered limitations of the research study.

- Although the research findings were remarkably consistent with findings of other larger scale research projects, they were drawn from a small sample. Due to time constraints and the required limited length of this study for academic purposes, the researcher did not select a larger sample group. However a larger sample size would have enhanced the degree to which the results could have been generalised thereby increasing the study's external validity.

- It was necessary for the researcher to use a translator during the research interviews, as the participants were Xhosa speaking. The translator was specifically chosen due to her experience and skill in this position. However it must be noted that the meaning of participants' words may have been interfered with during the translation process.

6.2 Recommendations

The following recommendations for further research and action are based on the research findings and the researcher's own experience whilst conducting the study.

Further psychological research should be conducted to explore the emotional needs of older caregivers so as to preserve their capacity to look after their family members infected and affected by HIV/AIDS. It was evident from the research process that the participants valued and benefited from the researcher's home visits, which involved the participants sharing their lived experiences of loss and their fears for the future. Over the course of three interviews the participants expressed feeling helped by the visits. There was no remuneration for their involvement in the project however they expressed that talking about their experiences was valuable and to them this was their remuneration. Home visits which include not only the assessment of a family's material needs but also their psychological needs will better support families struck by HIV/AIDS.

Further HIV/AIDS research should include the investigation of the impacts of the death of an adult child on elderly parents, as this is largely underreported in current HIV/AIDS literature in South Africa. Particular emphasis should be placed on themes of untimeliness, the unique parent-child bond, the impact of the loss on the whole family, the loss of potential supporters, role realignments in families after such a loss and parents' feelings of hopelessness for their future. This research highlighted the importance of these themes in understanding the complexity of parental responses to the loss of an adult child to AIDS. Further research in this area will contribute to a better understanding of the psychological strain which elderly parents endure when their lives are struck by their children's HIV/AIDS-related deaths.

Psychological support and counselling should be provided to parental caregivers both during caregiving and after death. Issues of secrecy and stigma should be challenged so as to break down the barriers these cause to effective access and utilization of support.

Most policies and action programmes in South Africa regarding HIV/AIDS emphasise its socio-economic, material and other practical impacts on families. However it is evident from this study that families, in particular caregivers, experience a range of psychological impacts in combination with socio-economic impacts when their families are struck by HIV/AIDS. Further research, which highlights the psychological dimensions of the impacts of HIV/AIDS on families will serve to enhance literature on HIV/AIDS in South Africa and its impacts on the African family and its caregivers.

APPENDIX ONE

The following are brief descriptions of the research participants, their families, their living conditions and their descriptions of their loss.

Mrs N

Mrs N is a 56 year old woman. She is of medium height and is slightly round. She has a soft maternal disposition. She has large bright eyes which have a friendly gaze. Her face is scarred on both cheek areas with pink discoloured skin. Mrs N went on disability grant after being hospitalised some years ago with severe sores on her face. She could not say what the cause of her skin reaction was but a nurse suggested that the scars resembled facial sores that result from syphilis infection. Mrs N may have contracted syphilis from her husband's unsafe sexual promiscuity which she referred to at times during the interviews. Mrs N wore bright pink and blue dresses at our meetings. Her feet were always bare and her hands were tough with rough calluses from her work picking prickly pears. She sat calmly during the interviews, occasionally she cried softly and held the apron of her dress to her face. Small grandchildren aged no more than 3 or 4 ran in and out of the house. They clung lovingly to Mrs N as she gently and patiently ushered them from the room where the interviews were taking place. Background gospel music and lively church sermons played quietly from the kitchen radio. Her daughter prepared food in the kitchen and her husband sat with a friend in the sun on the grass in front of their house. Mrs N has been married to Mr N for many years. Mr N is 70 years old. Although Mrs N initially described her marriage as being wonderful she later admitted that there have been more bad times than good. Her husband used to physically abuse her and had numerous extramarital affairs. Mrs N explained that because her husband has grown old now he no longer beats her or has affairs. However he has taken to verbally abusing her which she described as very painful. Mrs N had seven children, three girls and four boys. Her eldest son died last year in June from AIDS. He was 41 years old and was married. His wife died of AIDS one year before him. They had three children. The eldest child who is 12 years old is HIV positive. The three children live with Mrs N along with 8 other grandchildren. Mrs N is the primary caretaker of all the grandchildren. There are 13 people living in Mrs N's household. They survive economically off Mrs N's disability grant and her husband's pension. She also sells prickly pears for extra money but this does not render much. Mrs N cared for her son for 3 months during the end stages of his life. She

explained how she suffered silently during the time that she cared for her son as she felt there was nobody to talk to. She reported that the most painful time was when her son lost both his hearing and his speech. Before the time of the research Mrs N had never spoken to anyone outside of the family about her son's death.

Mrs M

Mrs M is a 71 year old woman. She is a short woman who holds herself upright with a strong posture. She maintained direct eye contact throughout our meetings and displayed a hard firm disposition. She is blind in one eye. She described herself as old and sickly although her disposition contradicted this description. She was consistently well turned out at all our meetings and wore dark shaded woollen hats, which covered her grey hair. Her husband is 72 years old. Most days he sits quietly in a lounge chair in the house. On the days of the interviews however Mrs M ordered him to sit in a small patch of shade outside while the interviews were in progress. He obeyed cheerfully and gave a warm smile and wave each time the research team arrived and departed. There are six people living in Mrs M's house and many grandchildren who live in nearby streets come in and out regularly. They often stay for a meal and Mrs M's helper washes their school clothes. Mr and Mrs M had nine children. Four children have died. Two children died at birth, another died a few years ago of cancer and last year their daughter died of AIDS. Mrs M's daughter had been married for some years before her husband died. Mrs M reported that he had died of unknown causes. Mrs M's daughter some time after the death of her husband became involved with another man and fell pregnant. When she went to the doctor to confirm her pregnancy the doctor had informed her that she was HIV positive. Mrs M recalled that her daughter had said she was shocked by the news, as she had not suspected it. When Mrs M's daughter became increasingly sick her partner abandoned her and his child who at birth had been diagnosed HIV positive. Mrs M expressed much anger and resentment at having lost another child. She also felt angry that her daughter had abandoned her with sick grandchild. Mrs M has kept her grandchild's diagnosis a secret, as she is afraid of telling a young child that she has the same sickness that killed her mother. Mrs M reported that with the strain of caring for her daughter and the worry she experiences over her grandchild have caused her to age much quicker and that her life has been shortened by all her sadness. There was much interest in the research team's visits to Mrs M's house amongst the neighbours who past the house and peered in to see what was transpiring. Mrs M smiled and waved them on their way and continued to talk to us. She

expressed her belief that AIDS should be spoken openly amongst people and that secrecy is not good. However in contradiction to this, she admitted that she would not speak openly to her sons about the disease despite acknowledging that they partake in casual sexual relationships. She felt it was not her place to challenge her sons about their sexual practices or speak to them about the importance of protected sex. She believed that if she spoke to them about these matters they would become angry with her and leave home. She felt afraid of this.

Mrs K

Mrs K is a 60-year-old woman. She is tall and slender woman who has a timid disposition. She lives in a small mud house, which is dark and cool inside. When the team arrived Mrs K greeted us and left her basins of washing to show us inside. Little sound came from the house except for the occasional entering of one or two grandchildren who came to the kitchen for a slice of bread after school. Her husband tended to a small vegetable garden at the back of the house and when resting sat under a tree watching the neighbours pass by. At every meeting Mrs K wore an old dress. She had a scarf wrapped around her head which she spent most of the time having to undo and redo as it loosened while she sat and spoke to us. She avoided eye contact when she spoke and anxiously moved her hands continuously during the interviews. Mrs K's sadness was striking and she awkwardly dried her tears on her dress throughout our meetings. She found it extremely difficult to talk about the death of her daughter and moved restlessly as struggled between talking and fighting back her tears. She had not spoken to anyone about her daughter's death before. Her daughter died of AIDS in October last year. She had been divorced from her husband some years earlier and a year ago became involved with another man. Mrs K reported that her daughter had been shocked to hear that she was HIV positive. Mrs K described feeling overwhelmed with fear at the thought of her future without her daughter, as she had been the family's breadwinner. Mrs K's grief recalled for her the sadness she had felt when she lost two other children. Some years ago she had lost a son at age 20 who died in a car accident and first born had died at birth. She explained how she had never spoken to anyone about her baby's death before. The grief she experienced after her daughter died she described as being the grief of all three children's deaths. Now there are eight people living in Mrs K's house. She looks after five grandchildren. The household's only source of income is Mrs K's disability grant which was granted to her at the beginning of this year. Mr K does not receive an old age pension as his

Identity Book claims he is younger than his actual age. Mrs K reported that her husband refuses to have the book corrected, as he is too proud to argue with the officials about his age, he had said to Mrs K that he felt it was insulting to have to do that. Mrs K described feeling overwhelmed by the prospect of having to sustain her family without the help of her daughter and her husband.

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