

**A comparative study of Bereavement between AIDS related and non-
AIDS related deaths.**

Sherona Rawat

Submitted as the dissertation component in partial fulfilment of the requirements for the degree of Masters of Social Science (Clinical Psychology) in the School of Psychology at the University of Kwa-Zulu Natal, Pietermaritzburg.

June 2006

Abstract

This study investigated the differences and similarities in bereavement due to HIV/AIDS and bereavement due to other forms of death. The participants comprised of nine (9) mothers and two (2) fathers of deceased children, varying in age from eight (8) months to twenty (20) years.

A single, unstructured interview was used to collect the data. Grounded theory was utilised in the analysis of the qualitative data. Comparisons were drawn between HIV/AIDS and non-HIV/AIDS related bereavement.

The findings indicate a difference in the experience of HIV/AIDS related bereavement and non-HIV/AIDS related bereavement. Stigma played a significant negative role in the experiences of those parents/caregivers whose children had died from HIV/AIDS. In addition, parents/caregivers experienced significant feelings of responsibility for their child's infection although the child had not contracted the disease from the parent.

The implications and applications of this study are twofold. Firstly, a better understanding of the bereavement process can result in important and innovative recommendations being implemented in order to refine existing HIV/AIDS intervention programmes or develop new ones. And, secondly, it can result in a more refined approach to the care and comfort that is currently being provided for HIV/AIDS patients and terminally ill patients and their families.

ACKNOWLEDGEMENTS

I would like to express my greatest gratitude to my supervisor, Professor Graham Lindegger, for his patience, guidance, encouragement, support and compassion. Thank you for being not only a great supervisor but also a friend, and a mentor.

In addition, I am grateful to the moms and dads who so generously agreed to be interviewed. Their willingness to share, their courage in broaching such a painful experience and their selflessness in wanting to help others who have suffered the same faith is deeply and graciously appreciated.

I would like to thank my children, Nazeera, Waseem and Azeza for their patience, support and faith. The sacrifices they have made have not gone unnoticed. I would like to thank my parents, Ferial and Ebrahim Rawat, for providing financial, emotional and practical support for my children and myself. In addition, I would like to thank my brothers, Mohamed Rawat and Dr Shiraz Rawat, and their wives, Razeena and Farzeen, and their children Azizuallah, Aminah and Aadila for their support and assistance. I would also like to thank my cousin, Dr. Somayya Coovadia for her understanding, emotional and financial support.

Without my children, my family, friends and my supervisor's unfailing support and extraordinary generosity, the completion of this research dissertation would not have been possible. May God bless you all.

DECLARATION

This thesis was undertaken at the School of Psychology, University of Kwa-Zulu Natal, Pietermaritzburg. Unless specifically indicated to the contrary in the text, this thesis is a product of the author's own work.



Sherona Rawat
Pietermaritzburg
June 2006

Table of Contents

Title page	1
Abstract	2
Acknowledgements	3
Declaration	4
Contents	5
Chapter 1: Introduction	11
Chapter 2: Literature review	15
Introduction	15
1. Mourning	16
a. Definition of key terms	16
b. Psychoanalytic perspective to mourning	16
c. Tasks of mourning	18
d. Stages of dying	20
2. Grief	23
a. Kinds of grief	23
b. Normal responses to grief	23
c. Resolution of grief	27
d. Unresolved grief	29
3. Factors that affect the grieving process	32
a. Nature of the death	32
b. Attachment and grief.	33
c. Communication between role players in the	38

bereavement process	
d. Children’s understanding of death	42
e. Religion and spirituality in the grieving process	45
f. HIV/AIDS and bereavement	45
4. Conclusion	53
Chapter 3: Methodology	55
1. Rational for study	55
2. Aim	57
3. Design	57
4. The qualitative approach	57
5. Grounded Theory	58
6. Method	61
a. Sampling method	61
7. Procedure	66
a. The interview	67
8. Data analysis	70
a. Constant comparison	72
9. Ethical considerations	72
Chapter 4: Results	75
1. Introduction	75

2.	Key demographics of participants	75
3.	Themes	76
a.	Grieving as coping alone	76
i.	Isolation	76
ii.	Misunderstood	77
b.	Fluctuations in grieving	78
i.	Shock/ disbelief	78
ii.	Guilt	79
iii.	Hope	80
iv.	Anger	82
v.	Denial	84
vi.	Expressions of grief	86
c.	Anticipatory grief	87
d.	Role of religious belief in the grieving process	88
e.	Focus on the future	92
f.	Social environment	94
i.	Counselling or help seeking behaviour	94
ii.	Altruistic behaviour	96
iii.	Cultural issues	96
iv.	Social attitudes, pressures and restraints	98
v.	Social support	99
g.	Family relationships	100
i.	Marital relationship and the grieving experience	100

ii.	Enmeshed relationship with deceased and the grieving experience	103
iii.	Routine and the grieving experience	107
h.	Regrets expressed by participants	108
i.	Ordinal position in grieving	110
j.	Exposure to loss- Multiple deaths and early death experiences	110
k.	Ability to converse adequately about deceased	112
4.	Comparison of HIV/AIDS deaths and Non-HIV/AIDS deaths	115
a.	Social support and stigma and its effects on HIV and non-HIV related deaths	116
b.	Religious belief and the implications for HIV and non-HIV related deaths	118
c.	Responsibility and culpability in HIV infection and transmission	119
d.	Cultural implications for loved ones afflicted by HIV and non-HIV related deaths	121

Chapter 5: Discussion	123
1. Introduction	123
2. Major findings regarding mourning	124
i. Social and relational aspects of the grieving process	124
a) Family relationships, attachment and the grieving process	124
b) Birth order and grieving	128
c) Exposure to multiple deaths	129
d) Loneliness and isolation	131
e) Grieving as coping alone	132
f) Conversing about the dead	134
ii. Fluctuations in grieving	135
a) Stages of bereavement	135
b) Normal and abnormal grief	137
c) Hope and focus on the future	138
d) Anticipatory grief	141
e) Regrets and guilt	143
f) Family reorganization and adjustment to loss	144
g) Anger	146
h) Denial	147
b. The comparison of death due to HIV/AIDS and non-HIV/AIDS death in the South African context	149

i.	HIV related stigma and grief	149
ii.	Guilt at causing death	150
iii.	Religious belief and the grieving process in HIV and non-HIV deaths	150
2.	Conceptual overview of results and implications of the study	155
3.	Limitations of the study	157
4.	Conclusion	158
	References	160
	Appendix: Interview schedule	169

Chapter 1.

Introduction.

The construct of society as a whole has never been as challenged as it is today by HIV/AIDS. In relation to sex and sexuality being in existence from the beginning of time, HIV/AIDS is relatively new. HIV/AIDS is spreading at an astounding rate. It has affected the developing countries rather than the developed countries to a greater extent. Attempts to curb or dissipate the consequences, repercussions and devastation that it leaves in its trail have failed. In relation to HIV/AIDS, the situation in South Africa is critical compared to the rest of the world.

The impact of AIDS on society is well recognised and the seroprevalence rates speak for themselves. At the end of 2002, 29.4 million of the 42 million adults and children living with HIV/AIDS were located in Sub-Saharan Africa (Lovelife, 2001). South Africa is the epicentre of the AIDS epidemic in Africa. Approximately 23.1% of our 44.8 million people in South Africa are infected with HIV/AIDS (Lovelife, 2001). Hence, of these 29.4 million individuals in Sub-Saharan Africa infected with HIV/AIDS, 10.4 million are South African.

During the period 1994 to 2001, there had been an exponential growth of HIV infections in South Africa (Lovelife, 2001). The rate of infection had risen from less than 1% in 1990 to 25% in 2000 (Anderson, 2000). This rate of growth

far surpasses the average rate of growth worldwide. Not only has the infection rate increased but also the disease is progressing from HIV into AIDS at a faster rate.

In 2000, an estimated 600 000 children aged 14 years or younger became infected with HIV (Lovelife, 2001). Almost 9/10 of these new infections occurred in Sub-Saharan Africa. During 2002, of the total estimate of 2.4 million deaths due to HIV/AIDS in Sub-Saharan Africa, 550 000 were children under the age of 15 years. Most of these infected populations who are not on antiretroviral treatments will die in the next 10 years, joining the 13.7 million Africans already claimed by the epidemic (Lovelife, 2001). Simply put, more children are being infected than adults and the infections are occurring earlier in the child's life. Consequently, this study touches on this issue by analysing the bereaved parents/caregiver's responses to their children dying as a result of HIV/AIDS. In order to gauge the difference between the bereavement process due to HIV/AIDS and the bereavement process in relation to other causes, the parents/caregivers in this study comprised of parents/caregivers of children who died due to HIV/AIDS related disease and children whose death was not HIV/AIDS related.

It is obvious from such statistics that not only are hundreds of individuals being infected every day, but also thousands of lives are being lost each year. Preventative educational programmes have not been very successful thus far and are no doubt compounded by racial, cultural and gender issues (Population Council, 2001; Russel, 2000).

To date the researcher has not come across any studies that focus on the bereavement process in relation to HIV/AIDS or ones that attempt to draw a distinction between bereavement due to HIV/AIDS and bereavement due to other causes. Studies of bereavement (e.g. Corless, Germino and Pittman, 1994) tend to focus on the description of the grieving process, books aimed at the Mental Health Professional like Worden (1982), the parent-child relationship such as Rubin and Malkinson's study (Stroebe, Hansson, Stroebe and Schut, 2001) or books that focus on cultural differences in the grieving process as documented by Rosenblatt (Stroebe et al, 2001). Many booklets and pamphlets are available that describe the scope of the disease such as those published by Love Life or on HIV/AIDS and Gender published by the Norwegian Working Group based on the Living for Tomorrow Project on Youth, Gender and HIV/AIDS prevention (Lewis, 2002).

Given the seroprevalence of HIV in South Africa, we can assume that there is a strong possibility that many members of the population have been, or will be, affected by bereavement due to an AIDS related death. Despite the extent of deaths related to HIV/AIDS, there is little evidence of studies that focus on the bereavement process in relation to HIV/AIDS or of studies that attempt to compare bereavement due to HIV/AIDS and bereavement due to other causes. An understanding of the bereavement process family and parents/caregivers of people who have died from HIV/AIDS will lead to intervention processes and strategies being developed. These intervention

strategies will take into consideration the specific psychological needs of this population.

Investigating the difference between bereavement due to HIV/AIDS and bereavement due to other causes is important in order to understand and facilitate grieving in HIV related deaths. It is imperative that one acknowledges that while there are likely to be many characteristics that are common across the grieving process, there is likely to be many aspects of grieving that are unique to HIV related deaths.

The purpose of this study to investigate whether bereavement due to HIV/AIDS is different from other forms of bereavement. The findings of this study are likely to result in delivery of more appropriate or fine tuned interventions specifically targeted at the bereaved parents/caregivers suffering from the loss of a loved one due to AIDS.

Chapter 2

Review of Literature

Introduction

In life we are all forced to face two “existential dichotomies”. The person going through a grief experience has to face both. One is death and the other is the feeling that life is too short for a man to find his fullest self-realization (Erich Fromm, in Jackson, 1985). Hence, many adults may retain a fear, which could manifest as a wish to avoid both the dying and the bereaved. This discomfort may then be intensified when the death involves a child (Bertoia, 1993).

The death of any child represents a loss of future dreams, future relationships, future experiences, future fantasies which we have not yet enjoyed and are not even able to place within a context of rational discussion (Grollman, 1995; Knapp, 1986). “Infant and child death can be viewed as more tragic and traumatic than the death of an older person because it appears to be accepted by society as less likely to occur” (Knapp, 1986, p.14). Hence, Knapp (1986) is supported by Grollman (1995) and Kalish (1980) when he contends that it is because of these above mentioned social ideals which imply that death is likely to occur in old age only that few norms have been developed or have survived in the past to guide loved ones, parents/caregivers in coping with the aftermath of the death of a child. In addition, he claims that this scenario has resulted in significant adjustment problems associated with the loss of infants and children for grieving parents/caregivers.

Mourning

Definition of key terms

There is a distinction between bereavement and mourning. In a review of the literature these terms are used interchangeably. However, for clarity it is necessary to examine theoretical definitions. Kaplan and Saddock (1995) quote the Committee of Health Consequences of the Stress of Bereavement, appointed by the Institute of Medicine in 1982 as defining bereave as “loss through death” and mourning as the “social expressions of grief, including funerals, visitations and rituals” (p. 1722). Therefore, by definition healing from the loss of a loved one involves two separate but parallel processes, viz. coming to terms with feeling abandoned by the loved one, while simultaneously remembering and acknowledging the extent and impact of the loss (Kavanaugh, 1974; Knapp, 1986).

In addition, the dictionary defines coping as to strike back or fight (Ilson, Crystal, Wells, and Long, 1988). Hence, with reference to the above-mentioned definitions of mourning, coping and grief, to mourn actively and willingly to work through the grief is to cope. To mourn is to fight back; mourning is a process of purging oneself of the loss. It is an instance whereby we work or fight to rid ourselves of bitterness, anger, guilt, and sorrow. Hence, coping with grief means allowing oneself to mourn a loss actively (Knapp, 1986).

Psychoanalytic perspective on mourning

From a psychoanalytic point of view (Freud, 1950 & 1957), re-investing energy into another object helps in the resolution of grief. Whereas from a

psychoanalytic perspective, it may well be that identification of the loss of an object is a general condition under which the ego will relinquish its object. “Apparently for a normal person it is easier to loosen the ties with an internal representation of a lost object than with an external object. Hence, the establishment of an internal representation of the lost object is a means of facilitating the final loosening of attachment to the deceased individual. Consequently, mourning consists of two acts, the first is an establishment of an internal representation of the lost object, while the second is the loosening of the binding to the internal representation of the lost object” (Fenichel (1945), in Kalish, 1980, p. 74). Freud’s (1950) notion on the loosening of the cathexis to the internal object differs from that of Fenichel (1945, in Kalish, 1980). While Freud views the internalization of a lost external object as part of the mourning process, he contends that through the process of catharsis, the energy from the introjected object is transformed or transferred into another object rather than “loosened” as in the case of Fenichel (1945). Hence, Freud takes the psychoanalytical description of the mourning process one step further in that he foretells the likelihood of the individual’s development of a new attachment.

“As the first involves the effort to destroy the pain of grief by a maneuver that internalized, incorporated and identified with a lost loved object so the second seeks to destroy the pain of grief by an active effort to externalize, project and substitute an image or an object for that, which has been lost” (Kalish, 1980, p. 75). Hence, according to Kalish (1980), the grieving person may seek to invest his emotional capital in something or somebody else, as well as form an internal representation of the lost external object.

According to Freud (1957) being emotionally bound to someone means investing libido in that individual. Freud (1957) contends that the essence of grief work is to reclaim libido from the deceased person for subsequent relationships and commitments. “To the extent that a bereaved individual is ambivalent about the lost partner, he or she may have trouble accomplishing decathexis” (i.e. doing grief work) (Shaver, in Stroebe et al, 2001, p.71). In addition, anger may be contributing to the continuation of ambivalence and feelings of guilt toward the deceased person.

In regard to children, many theorists (Kaplan and Saddock, 1995; Nagera, 1970; Wolfenstein, 1966) maintain that children are unable to fully mourn major losses. The major reason for this argument rests on the psychological and emotional maturity of developing children. Nagera (1970) described how the child’s proclivity to use denial, his/her inability to tolerate the prolonged painful affects of grieving, their greater degree of ambivalence in object relations, and their frequently distorted concept of death because of concrete and egocentric thinking all prevent the resolution of mourning in childhood losses. In order to mourn a person’s death, a child must distinguish that person as a separate and unique individual and must recognize the permanence of the loss. However, according to Bowlby the maturation required for this usually only achieved by age two to three (Bowlby, in Leon, 1990).

Tasks of mourning

Kalish (1980), Kaplan and Saddock (1995), Knapp (1986), Rando (1993) and Wolfelt (1991) maintain that a broad distinction can and should be drawn between

mourning as a self-limited, healing process in which a resumption of prior functioning is achieved and the multiple forms of unresolved grief, either as an arrest at one of the phases of bereavement (for example, inhibited grief or chronic mourning) or as a pathological variant (for example, hypochondriasis), in which serious impairment in functioning persists (Bowlby, in Leon, 1990). Consequently, while the manifestation of the mourning and bereavement can and does differ among individuals, it is imperative that the individual progresses through the different stages of the grieving process in order to resolve their grief. Unresolved feelings stagnate the individual, causing him or her to fixate at the point of most dissonance. In so doing, the individual may sever other relationships or adopt maladaptive behaviour patterns, which could have negative implications for other family members (Alexander and Alderstein, 1958; Brown, 1999; Fogarty, 2000; Grollman, 1995; Kalish, 1980; Kaplan, 1971; Knapp, 1986; Matinson, Gillis, and Colaizzo, 1990; Parkes, 1972a, in Brown, 1999; Saukes, 1987; Spinetta, 1984). Hence, the maladaptive responses of the parents/caregivers can have far reaching consequences for the surviving offspring.

Worden (1982, 1991) suggests that there are four tasks of healthy mourning. They are: - To accept the reality of the loss; to experience the pain of grief; to adjust to the environment in which the deceased is missing; to withdraw emotional energy and to reinvest in another relationship and while the fifth task of grief taken from Wolfelt (1988) is to convert the relationship with a deceased from one of presence to a relationship of memory or according to Freud (1950 & 1957) to re-invest the psychic energy in internal representations.

Dane and Miller (1992), Kavanaugh (1974) and Worden (1982 & 1991) describe different stages of grief. Dane et al (1992) refer to the first stage being a period of shock, numbness or disbelief and stages 2 – 8 dealing with resolving related emotions such as pining, depression, guilt and anger. Kavanaugh (1974) identified seven stages described as shock, denial, disorganization, violent emotions, guilt, loss and loneliness and relief and reestablishment. Dane (1992) claims that the above-mentioned stages are likely to have run its course after approximately one year or more do not have a fixed sequence and not everyone goes through all the stages. However, Kavanaugh (1974) claims in reference to the above-mentioned stage of loss and loneliness that the resolution of this stage can last “from a year to a lifetime” (p.142).

Stages of dying

Two aspects of the dying process seem to be important in conceptualising individual grief processes and responses. One is the stages that the individual passes through while in the process of dying (Kalish, 1980; Kavanaugh, 1974; Knapp, 1986; Kubler-Ross, 1969; Rando, 1993; Worden, 1991; Wolfelt, 1991) while the other is acknowledging that the dying individual is not only involved with his own stage of grief but also those of his loved ones (Grollman, 1995; Kavanaugh, 1974; Fogarty, 2000). Hence, the dying individual carries a dual burden. That is they have not only the burden of dealing with their own grief but also have to endure the unfolding of their dying loved ones acceptance of his impending death (Brown, 1999; Kalish, 1980; Knapp, 1986). The stages of dying theorized by Elizabeth Kubler-Ross (1969): denial, anger, bargaining for life, acceptance, and detachment (Bracken, 1986) sheds

some light on basic states that an individual might pass through. However, Kavanaugh (1974), in discussing his conception of a grieving process pointed out that the seven stages he envisioned closely paralleled the five stages observed by Elizabeth Kubler-Ross in her work with dying patients who were aware of their impending death. However, unlike Kubler-Ross's stages, the Kavanaugh stages seem more relevant to the grieving experiences of the survivors rather than to those who were themselves dying in that they allow for the survivor to resolve the grief reaction and move on to "re-establish" a new, post bereavement existence. "The seven Kavanaugh stages combine into six for the purpose of this discussion are defined as: 1. shock and denial 2. Disorganization 3. Violent emotions 4. Guilt 5. Loss and loneliness and 6. The twin stages of relief and reestablishment" (Knapp, 1986, p.127). There is however, controversy over the different stages.

It is reported that terminal adults and children pass through the five (5) stages of acquisition of factual information during the grieving process (Bluebond-Langner, in Bertioia, 1993). The stages they pass through are described by Bertioia (1993) as: -

1. Recognition that it is a serious illness, 2. Interest in the names of drugs that they would have administered and the possible side effects, 3. Purposes of treatment and procedure, 4. Disease as a series of relapses and remissions (- death) and 5. Disease as a series of relapses and remissions (+ death) (p.11).

However, not all children will pass through all these stages or will complete the stages in the same order.

According to Bluebond-Langner (1978) individuals require a change in their personal perception of their individual life circumstances in order to resolve their grief reaction. Bluebond-Langner (1978) contends that hospitalized, terminally ill children progress through five stages of changing self-concepts, finally viewing themselves as dying. Bluebond-Langer found that what the children were able to communicate depended strongly on the perceptions of adult expectations of them and on what any given adult could tolerate (Blueblond-Langner, in Bertoia, 1993). The five (5) stages of change in concept he describes are “1. Recognition by the child that s/he is seriously ill, 2. Recognition by the child that s/he is seriously ill – but will get better, 3. Recognition by the child that s/he is always ill – but will get better, 4. Recognition by the child that s/he is always ill – and will never get better, and 5. Recognition by the child that s/he is dying – hence, terminally ill” (Bluebond- Langner, in Bertoia, 1993, p. 11).

Kaplan and Saddock (1995) concur that different players in the scenario passing through different stages of different cycles at different times further complicate the dying process resulting in parallel grief processes. Hence, in many instances, due to anticipatory grieving, a survivor may emotionally detach from the dying individual at a time when he or she may most need them (Grollman, 1995; Kalish, 1980; Knapp, 1986).

Grief

Kinds of grief

Knapp (1986) contends that in relation to a dying child, especially one whose death is slow and prolonged, parents/caregivers are forced into the situation of giving care and comfort over the period of several months to a child they know has no future. This scenario may lead to different forms of abnormal grief reactions (Natterson and Knudson, 1960; in Kalish, 1980): anticipatory grief (Kalish, 1980; Knapp, 1986); complicated grief (Wolfelt, 1991); delayed mourning and absent mourning (Rando, 1993); and what Kaplan and Saddock (1995) call pathological grief or impacted grief, Knapp (1986) calls shadow grief and Kavanaugh (1974) and Wolfelt (1991) refer to as chronic grief.

Normal Responses to grief

Researchers such as Knapp (1986), Grollman (1995), Kalish (1980) and Kaplan (1971) express the opinion that an overwhelming characteristic of all parents/caregivers they have come across who have suffered the loss of a child is likely to be expressed in the form of a need that makes a loss of a child different from other kinds of losses. The defining characteristic of grief due to the loss of a child is in that this need is described as a need or desire to never forget or always remember the deceased. "They fear that they will forget the sight of the child's face, the sound of his/her voice, the texture of the child's hair, the uniqueness of the hands, even the child's characteristic smell. Parents severely miss these sensual experiences and eventually come to wish to retain them in memories as long as they live" (Knapp, 1986, p. 29).

Guilt was one characteristic that was commonly associated with the grieving process (Fogarty, 2000; Kalish, 1980; Kavanaugh, 1974; Knapp, 1986; Rando, 1993). Knapp (1986) found in his study of bereaved parents/caregivers that all parents/caregivers indicated that they felt and experienced guilt at some point during bereavement period. He goes on to say that parents/caregivers are likely to “feel guilt that they might again come to enjoy life that they might achieve some degree of normality in their life patterns. Many actually fear this eventual recovery believing that it may imply that they thought the death of their child didn’t matter. It was as if they were intentionally hanging on to these negative feeling as an assurance that their child was important” (p.144). Knapp is supported by Grollman (1995) when he goes on to say that some parents/caregivers eventually do not fear death or dying and contemplate their own death as a way of legitimising the loss.

As mentioned earlier, experiencing feelings of guilt is a common reaction to the death of a loved one (Fogarty, 2000; Kalish, 1980; Kavanaugh, 1974; Knapp, 1986; Rando, 1993). However, Kalish (1980) contends that in some individuals, an individual experiencing uncertainty and fear can easily stimulate the feelings of guilt. This individual may then become excessively vulnerable to these feelings of loss. This vulnerability to his or her own strong emotional reaction may then result in a pathological response to the grief experience (Kalish, 1980), rather than substitution of the deceased loved one as mentioned previously. The grief experience may trigger a variety of suppressed emotional responses and feelings rooted in preconscious or unconscious levels of their mental life (Alexander and Adlerstene, 1958; Grollman,

1995; Kalish, 1980; Knapp, 1986; Natterson and Knudson, 1960; Parkes, 1972a, in Brown, 1999), in some cases, this may include the assumption that the individual is incapable of grieving such as with the very young, the elderly, the mentally retarded, and the mentally disturbed (Randoo, 1993). In these individuals, the emotion that is inarticulate may result in actions that do not serve the best interest of the person involved. Hence, in order to deal with the emptiness of the future produced by the death of a child these parents/caregivers fill the void with the images of that child they once had, with thought, memories and open discussion, to the preclusion of all else. Only in this way does such a loss become a reality to them (Knapp, 1986).

According to Knapp (1986) anger at the death of a child manifests itself differently with mothers and fathers. He claims that most fathers' often-direct anger out and mothers often turn anger inward. In either case, the manifestation of the parents/caregiver's anger often takes the form of sarcasms, silence, withdrawal, demanding love and affection or at other times may be directed at other children. In addition, Knapp says that this anger can also be transformed into guilt or self-blame for not having paid adequate attention to early warning signs or not having gone sooner to seek medical advice (Knapp, 1986). The death of a child can cause already existing problems within the marital relationship to become magnified (Kalish, 1980; Kaplan, 1971; Knapp, 1986). According to Knapp (1986) on average 30-70% of marriages that suffer the death of the child end in divorce. The end of the relationship usually comes during the stage of loss and loneliness, thus divorce is seen not as a cause of marriage dissolution but as symptom of the family's inability to deal realistically with this painful phase in a grieving process (Knapp, 1986).

In the terminal stage of the illness parents/caregivers need to reorient themselves to the changing needs of their dying child. As is the case with adults, children needs to be given time to prepare for their approaching death. "It is important to offer emotional support and guidance and share emotional concerns with the dying child. Many parents/caregivers reveal that they allow the role reversal to take place, many begin to think of their child as their mentor or teacher quite the reversal of the parents/caregivers to child relationship and they allow the child to control life segments of their lives. These changes can occur even if they are young children" (Knapp, 1986, p.49).

Children, like adults, resort to familiar patterns when they hear bad news or are anxious or afraid. Play is a familiar activity utilized by children when stressed. Play may be a means of returning to an activity that is familiar in an attempt to seek some control over a situation that seems so far beyond their control (Grollman, 1995).

Leon (1990) claims that the guilt depression and rage resulting from the bereavement can be perceived as being so crushing, unbearable and ultimately traumatizing that long-term coping with this loss appears to depend more on the opportunity to gradually accept this brutal reality through anticipatory grieving before the actual death than any other factor.

Resolution of grief

According to Kalish (1980), an important component in the parents/caregivers psychological development in relation to the adequate resolution of grief is an adequate attitude towards life and death. He contends that her behavior will manifest in the unconscious and preconscious levels of her mind and that these behaviors will impact on her day-to-day relations with the child. "Hence, the very nature of her biological relation to the child is a binding tie that is characterized by emotional content. Security in this relationship is basic to the development of emotional security. Ultimately, emotional security is important for effectively doing the work of mourning" (Kalish, 1980, p.36).

It is because of the above that grief states, irrespective of the nature of the loss, are not ended by replacement of the lost person (Fogarty, 2000; Rando, 1993; Weiss, in Stroebe et al, 2001; Wolfelt, 1989; Worden, 1982). Weiss's (2001) statement conflicts with the psychoanalytic view in that he believes that a replacement figure may reinforce the very mechanisms and maladaptive behaviours and thoughts that are causing the bereaved individual to remain stuck at a certain stage in the grieving process. Parkes (1972a, in Brown, 1999) agrees with Grollman's (1995) statement "...in response to a death children experience the same reaction that adults do but these reactions are expressed in different ways" (p.66). Hence, in light of Goldman's (1995) remark we can argue that although much of Fogarty's work is extracted from the experiences of children much of what he describes can be applied to adults as well. Fogarty (2000) disagrees with Weiss. He contends that the need to "recreate situations and experiences" (Fogarty, 2000, p.13) that include the deceased individual

have a purpose in that “the attempt to recreate is designed to fail” (Fogarty, 2000, p.15). Bereaved individuals need to experience and then say goodbye to their beloved, secure in the knowledge that there is no return, and nothing will ever replace their lost loved one (Fogarty, 2000; Weiss, in Stroebe et al, 2001). Hence, Fogarty (2000) claims that the failure to resurrect experiences and situations results in the maximization of denial. The most agonizing feature of this process that is, evoking visceral memories of the deceased is a key element in resolving grief (Fogarty, 2000; Grollman, 1995; Kaplan, 1971; Leon, 1990). According to Knapp (1986) and Kavanaugh (1974) the refusal of parents/caregivers to talk about the deceased child results in the extension of the grieving process over a greater period of time. In addition, the endeavour to avoid discussion regarding the death can also lead to the withdrawal from physical contact with others (Grollman, 1995) and to a tendency on the part of others to avoid the bereaved parents/caregivers (Kavanaugh, 1974), ultimately resulting in isolation and the loss of social support.

Kaplan (1971) goes as far as saying that the refusal to express painful emotions can have detrimental consequences for the marital relationship. An individual's inclination to propagate the false assumption that one can continue the relationship with the deceased as done previously, prevents the opportunity to evoke, savour and then relinquish precious memories of the deceased (Stroebe et al, 2001).

Unresolved grief

In normal grief reaction symptoms such as confusion, disorganization, apprehension and fear are present. However, these reactions are temporary and are worked through as the individual faces reality and deals with it even though the process of doing it is painful (Grollman, 1995; Kavanaugh, 1974; Knapp, 1986; Natterson and Knudson, 1960, in Kalish, 1980). In abnormal grief the loss may serve as a precipitating factor that releases unconscious fears related to unresolved early experience (Kalish, 1980). Then, the apprehension and dread refuses to be focused at the actual experience that precipitates it resulting in defused and disorganized expression. Normal grief and anxiety are clearly different from abnormal grief as they relate to the reality factor. The reality of the loss may be denied or the resulting emotions projected resulting in a grief response that further complicates the mourning process. Hence, abnormal grief and anxiety may turn into a chronic emotional state (Friedman et al, 1963, in Kalish, 1980; Kalish, 1980; Kaplan, 1971; Rando, 1993; Wolfelt, 1991).

The dynamics of the grief reaction may be learnt in at least four ways, firstly by the personality structure of the individual in relation to conscious and unconscious processes within the psyche of the individual (Alexander and Adlerstene, 1958; Grollman, 1995; Kalish, 1980; Knapp, 1986; Natterson and Knudson, 1960; Parkes, 1972a, in Brown, 1999), secondly by the social factors that are at work about the individual such as social support (Grollman, 1995; Kalish, 1980; Knapp, 1986), quality of marital relationship (Kaplan, 1971; Knapp, 1986), thirdly by the importance of the deceased in the life system of the individual (Bowlby, 1969; Grollman, 1995;

Kalish, 1980) and lastly by the value structure of the individual such as the setting of priorities and the altering of value systems (Kalish, 1980; Knapp, 1986).

Bereavement researchers such as Leon (1990) have identified three factors associated with unresolved mourning: ambivalence toward the deceased... extreme dependency on the deceased, and the sudden unexpected nature of the deceased. Karl Abraham comments in Freud (1950) that in a normal person the process of interjection is set in motion by real loss to preserve relation with the loved object to compensate for the loss but is never unaware of the loss. When the process is unconscious and not understood then the result within the personality is likely to be abnormal and show up in specific problems in behaviour (Freud, 1950).

Therese Rando (1993) describes six responses regarding complicated mourning. They are absent mourning (as if the death has not occurred at all), delayed mourning (full or partial mourning is eventually triggered), inhibited mourning (the mourning process consciously or unconsciously becomes and remains restricted to various degrees), distorted mourning (extreme anger or extreme guilt), conflicted mourning (arises after a loss of highly troubled and conflicted relationships after brief absence of grief even relief the mourner experience severe guilt, self-reproach as well as mixed feelings that characterized the pre-morbid relationship, unanticipated mourning (unexpected death or terminal illness including the main complicated issues associated with unanticipated loss) and chronic mourning (acute mourning that persists and does not abate)(Fogarty, 2000).

Wolfelt (1991) has offered the following typology of complicated mourning.

1. Absent grief: defines absent grief as, an absent grief no apparent feelings of grief are expressed.
2. Distorted grief: Alan Wolfelt (1988) defines a distorted grief as distortion that occurs in one above the normal dimensions of grief. This distortion may prevent the grief process from unfolding and the person often becomes a distorted dimension of the grief.
3. Converted grief: The person demonstrates behaviour and symptoms that result in personal distress however he or she is unable to relate their presence to the loss.
4. Chronic grief, defined as chronic grief as a person demonstrates a persistent pattern of intense grief that does not result in appropriate reconciliation. Essentially the mourner attempts to keep the person alive (Fogarty, 2000).

Chronic grief may be likened in some ways to shadow grief (Fogarty, 2000; Knapp, 1986). “Shadow grief will vary in intensity depending on the person and the unique factors involved, it is more emotional for some than for others. If the shadow grief exists the individual can never remember the loss without feeling some kind of emotional reaction regardless of how mild. The difference between normal grief and shadow grief is similar to the difference pneumonia and the common cold. The latter is less serious and less destructive to life more often ‘nuisance’ than anything else” (Knapp, 1986, p. 41).

Another more recent category of grief reaction is referred to as disenfranchised grief. Disenfranchised grief is the grief that a person experiences when there occurs a loss that is not or cannot be openly acknowledged, publicly mourned or socially supported. (Fogarty, 2000). Doka (1989) lists three types of disenfranchised grief: 1) The relationship with the deceased is not recognized, for an example an extramarital lover or a homosexual partner, 2) The loss is not recognized, as the loss is not defined by the society as significant, example death due to HIV/AIDS infection and 3) The griever is not recognized, a person may be socially defined as not able to grieve, and an example is the very young, the elderly, the mentally disturbed and the mentally retarded (p.79). This form of grief has become evident in recent years due to the stigma attached to deaths due to HIV/AIDS.

Factors that affect the grieving process

Nature of the death

The grieving process appears to be affected by the nature of the death (Grollman, 1995; Kavanaugh, 1974; Knapp, 1986). One of the most serious obstacles to the successful resolution of grief is the suddenness of object loss (Kavanaugh, 1974). Unexpected death has been described as more traumatizing than anticipated bereavement (Kavanaugh, 1974; Knapp, 1986; Parkes, 1986; Schoenberg, Carr, Kutscher, Peretz and Goldberg, 1974), much more likely to be experienced as overwhelming loss, followed by potentially long-term maladaptive defences and pathological variants of grief. These findings have been frequently reported by bereavement researchers (Parkes, 1986; Volkan, 1970, in Leon, 1990) and reveal a statistically significant increase in psychiatric morbidity among those who were

suddenly bereaved compared to those who expected the death (Lundin, 1984, in Leon, 1990). Anticipatory grieving, mourning an expected death often results in less devastating grief and a more benign outcome post-death than does a sudden loss (Bourke 1984, Rando 1986 a, in Leon, 1990).

Attachment and grief

Attachment theory posits a human instinct to form strong, persistent affectual bonds (Kaplan and Saddock, 1995). John Bowlby's (1969) interest in attachment was originally sparked by noticing the effects of maternal loss on children's later psychopathology and delinquency. Hence, attachment theory was designed to explain the psychological impact of loss (Shaver et al, in Stroebe et al, 2001). Consequently, Bowlby's interest in the effects of loss shown in psychopathology is not such a far cry from the impact of loss on maladaptive behaviour.

Grief is a natural reaction to loss. Attachment style is pivotal to the resolution of grief (Becvar, 2001). As grief is a social group experience, it involves the relationship with another person or persons (Jackson, 1985). Hence, before the impact of loss and grief can be fully understood the meaning of attachment needs to be explored. Bowlby's (1969) attachment theory describes a drive to establish affectionate bonds with others and a grief (response) that occurs when these bonds are threatened or severed. Bowlby argues that attachment comes from a human need for security and safety, which is prevalent throughout life. However he sees attachment as extending beyond the physical need of a young child, for example for food warmth

and comfort. The quality for attachment determines the capacity of a child to establish affectionate bonds later in life (Bowlby, 1969).

John Bowlby's (1969; in Parkes, Laungani and Young; 1997) attachment theory points to there being different attachment styles that lead to different attachment behaviours. A natural response to the loss of an attachment bond is separation anxiety, which generates intense but predictable behaviour geared to recoup or revive the lost relationship (Kaplan and Saddock, 1995). For instance, an insecurely attached child can either become very clingy or appear very independent.

Bowlby (1969) describes bereavement in relation to stages and the amount of time frame. He states that the first stage, shock and denial lasts a number of weeks, yearning and protest, also lasting a number of weeks, despair, which may be accompanied by somatic and emotional upset and social withdrawal, lasts several months or even years and the last being gradual recovery which is marked by increased well-being and acceptance of loss.

According to Ainsworth, Blehar, Waters and Wall (1978), the three attachment styles, referred to by Bowlby, are securely attached, avoidant and ambivalent. Ainsworth delineates four patterns of attachment (Ainsworth et al, 1978) they are:

Secure- (Ainsworth category B) parents whose sensitivity and responsiveness to their infant's needs for security and a safe base from which to explore the world are adequate, have children who tolerate brief separations

without great distress, and respond rapidly to their mother's comforting behaviour when she returns; insecure- (anxious ambivalent- Ainsworth category C) mothers who are overanxious and insensitive to their infants and discourage exploration have children who show great distress during periods of separation and who both cling to and angrily cry at their mother when she returns; avoidant- (Ainsworth category A) children whose mothers cannot tolerate closeness and punish attachment behaviour learn to inhibit clinging and crying. When their mother leaves the room they appear detached and uncaring. When she returns they often ignore or turn away from her. However, they show evidence of physiological arousal in a rapid heart rate throughout the period of separation and disorganized/disorientated (Ainsworth's category D) these children exhibit a wide variety of disorganized behaviour when separated. They often 'freeze' and may show stereotyped behaviour after mother returns.

These styles of attachment tend to persist over time. Unless challenged by a stronger bond or attachment it is likely to affect ones response to loss over time.

Recent work has shown these patterns of attachment in adults as well.

Parkes (Parkes, 1986; Parkes, 1987, in Curren, 2001) reiterates this thought by stating that as the bonds of attachment are broken, there comes a realization that their basic assumptions about themselves and about the world will have to change and this leads to a time of social withdrawal for many people while their world is being assessed (in Curren, 2001). Parkes believes this to be especially true in regard to "psycho-social transitions". Psychosocial transitions refer to the kind of loss that

brings about profound changes in the social environment of that individual such as the loss of a child. This scenario requires people to undertake a major revision of their assumptions about the world (Currer, 2001). Parkes further posits that these changes are lasting rather than transient, and takes place over a relatively short time so that there is no time for preparation. The effect of this on the child is that indicated by Kaplan's (1971) study of families of leukemia victims where effective coping by the use of open communication helps in the resolution of the grief reaction. As the family comes to accept the death their emotional involvement diminishes or become intellectualized and defused whereas the medical staff may be caught up in the drama of the death and their emotional investment in the patient may increase (Natterson and Knudson, 1960). The turning away of the family members at this time in a psychological as well as the physical sense can create a void for the patient at the time when he needs the support, comfort and reassurance of his family. The phenomenon of anticipatory grieve can serve to block such support. The absence of tears or expressions of concern may compel the patient to grieve not only for his own death but also for the seeming loss of his family's love (Kalish, 1980). Parkes resolution to this phenomenon is that preparation for the death and support is vital (1993, in Currer, 2001).

In addition, one is likely to prohibit and hinder the progress of the other surviving loved ones. Hence, one is always bound by the grief, always looking for the lost loved one, and consequently, always trying to replace the loved one by moulding others to be like him or her or by trying to force others to conform to predetermined

agendas. This phenomena is called the ‘continuing bonds’ theory – where the individual constructs continuing mental relationships with deceased attachment figures (Shaver, in Stroebe et al, 2001). The Dual Process Model (Stroebe, 2001) is a similar model to the Continuing Bonds Model (Shaver, in Stroebe et al, 2001), in that it focuses on the nature and extent of the bond between the surviving individual and the deceased. The Dual Process Model explores the parallel processes of resolving feelings of abandonment and experiencing the feelings of loss while the Continuing Bonds Model explores the development of the emotional bond over time. Secure people are expected to be more likely and able than insecure individuals to solicit and benefit from social support following a loss, be more optimistic than insecure individuals and to be better able to move between “loss orientated” and “restoration orientated” processes delineated in the dual-process model of coping with bereavement (Shaver, in Stroebe et al, 2001, p.80). In order to facilitate the grieving process, the attachment style of the bereaved individual needs to be identified and addressed (Bowlby, 1969). A halt in the grieving process can indicate a maladaptive attachment style (Shaver, in Stroebe et al, 2001).

The time frame governing all his or any other researcher’s stages appear to be speculative and the presence of any particular stage subjective. Although all the given stages may not be experienced and the process can take from a few weeks to any number of years to be completed, it is vital to acknowledge bereavement as a painful process and that acceptance of the loss, while not a cure-all, is a turning point.

Communication between role players in the bereavement process

Coping with emotional strain is dependent upon the individual's psychological reaction to the grief (Kalish, 1980) as well as social response that he or she receives or responds to (Brown, 1999; Fogarty, 2000; Grollman, 1995; Kalish, 1980; Knapp, 1986). In our society people are not prepared socially with respect to dying, as a result, the dying process is managed clinically and guided by policy and procedure is utilized in managing the death. These bureaucratic structure and goals that are incompatible with the process of dying (Kalish, 1980). Due to the inadequacy of the above-mentioned socialization process, "parents who have difficulty responding to each others' needs will approach the death of a child with a sense of loneliness and isolation and they will find themselves totally ill prepared for this tragic event when it occurs"(Knapp, 1986, p.51).

"Even though on the average two children die everyday from parental abuse the consistent view is that most parents are preoccupied with child rearing. They pamper their children and take great pride in their development. They take the task of parenthood very seriously" (Knapp, 1986, p. 120). Following the death of a child the agony within the family is pervasive and profound. For parents/caregivers a child's death represents a loss of their hopes, their dreams and their future. They are faced with emotions so intense as to be debilitating. For other children a loss of a sibling means a loss of playmate, a confident arrival, a role model, a friend but in case of a sibling loss a children's experience may be further complicated by the failure of those around him or her even to acknowledge that she/he has suffered a significant loss (Grollman, 1995).

Reactions due to impending separation frequently bring about awkward communication and even withdrawals are part of those emotionally attached to a dying person (Natterson and Knudson, 1960). Hence, grief, which is unexpressed or unshared, cuts off an important line of communication (Brown, 1993; Fogarty, 2000; Grollman, 1995; Kalish, 1980; Kavanaugh, 1974; Knapp, 1986; Parkes, 1972a). Children can even delay their own grief feeling that they need to support others (Grollman, 1995). Hence, the expression of fear and concern is crucial for a dying person. These are means of sharing the number of important feelings that ease a process, to some extent helping replace feelings of isolation and unexpressed grief (Kalish, 1980).

Bowlby (1969), Brown (1999), Fogarty (2000), Grollman (1995), Kalish (1986), Knapp (1980), and Natterson and Knudson (1960) concur that the impending death of a child has a profound effect on the relationship between the child and his or her parents/caregivers. For example, in some instances, when problems arise with communication, the child may try to protect the parents/caregivers by mutual pretense (Bertoia, 1993) about the impending death. Parents/caregivers may spend a large amount of time in the presence of children constantly assuring them that it's all right to feel the way they do (Knapp, 1986) when faced with a crisis such as a terminal illness. "The crisis of life invite this type of significant communication, but when bereavement comes it often dislocates the process by removing the one with whom communication has been most effective. So the problem of restoring communication may be doubly difficult" (Jackson, 1985, p. 232). Hence, social support structures

may become scarce or unavailable (Kalish, 1980). However, whenever children are suppressing or expressing their feelings they are never the less grieving and are affected by their parents/caregiver's expression of their own sorrow (Grollman, 1995).

Kaplan (1971) in a study of coping patterns in 50 leukaemia families described effective coping as characterized by open communication and discrepant coping, in which communication between parents/caregivers is restricted. Kaplan suggested when channels of communication remain between the parents/caregiver's feelings of grief, concerns, fears etc., when ready for expression may be shared openly with a spouse. The prohibition or expression of grief then compromises the ability of the family members to resolve important coping tasks and may have long-term detrimental consequences for the marital relationship (Kalish, 1980; Kaplan, 1971; Knapp, 1986). The erosion of the marital relationship may hinder the provision of social and emotional support between parents. Social support is an important component in the successful resolution of grief (Kalish, 1980).

In order to avoid a complicated or pathological grief reaction the family must have access to sufficient psychological and supportive resources in order to overcome the effects of the stressful event. Knapp (1986) cites that McCubbin and his colleague cite four kinds of resources available to a family, which are likely to moderate the personal effects of stressful encounters, these are family members personal resources: defined as financial, educational, health and psychological; the family system internal resources: defined as integration and adaptability; the social support systems

available; and coping techniques or mechanisms that may be available and operational.

Glaser and Straus (1967) describe a set of awareness-and-interaction types in relation to bereavement. These four basic awareness types emerge from the possible combinations of awareness and communication patterns, they are:

- 1) Closed awareness – dying person does not realize that he or she is dying and will not be told,
- 2) Suspected awareness – the patient suspects that the truth is not being told but will not be told,
- 3) Open awareness – both the patient and others are willing and able to share their knowledge and concerns and,
- 4) Mutual pretence – the patient and visitor know about the death but both pretend that they do not know ... others appear to be attributing their own anxiety to the patient... many terminally ill people, conditioned by their experiences with the illness and supported by their own maturity, are more prepared than their interactants to face the facts ...the underlying reality is often sufficiently unclear, uncertain and unstable, suggesting that nobody's version of the truth is beyond question (Kastenbaum, 1998, in Kastenbaum, 2000). It is therefore

clear that the interactions between those around the dying individual play a part in helping or hindering that individual's acceptance of his or her impending death.

Children's understanding of death

In order to foster communication and understanding between the parents/caregivers and the dying child it is imperative that we understand death from the perspective of the child. The findings of Nagy's (1936) classic research on children's conceptions of death provided evidence for the three alternate modes of understanding bereavement in children. In the first stage between the ages of three and five years children do not distinguish between death and separation; in the second stage between five and nine years, death is conceived as a permanent state; and in the third stage at 10 years and over children understand that death is real, inevitable and irreversible. Although this research was criticized for not taking culture and previous experience or loss into account, research conducted since this study appears to reiterate Nagy's point of view (Bluebond-Langner, 1978).

According to Bluebond-Langner (1978), children as young as 18 months can understand that they are dying and that the process cannot be reversed. Bluebond-Langner contends that the child's self-concept affects the bereavement process of the child. He cites five stages in the child's understanding of his or her illness and the terminal nature of the illness. They are, seriously ill, seriously ill but will get better, always ill but will get better, always ill and will never get better and dying. Hence, Bluebond-Langner also subscribes to Nagy's notion of children being able to

understand the inevitability and permanence of death. However, both the above-mentioned authors do not stipulate the age at which this becomes possible for the child.

Other researchers posit that children who are dying often know it without asking (Bach, 1969; Bertoia, 1993; Furth, 1981; Keipenheuer, 1980; Kubler-Ross, 1983 and Siegel, 1989), without being told even if they are young. Even before the children are consciously aware of their prognosis and revealing it in their symbolic verbal language, their art indicates a preconscious knowledge of their illness and outcome (Susan Bach, in Bertoia, 1993). The parents/caregivers may not know how to respond to this new child capable of thinking and talking about his/her condition in a very adult manner. The changes may be so great that they may disturb the parents/caregivers (Knapp, 1986).

Brown (1999), Fogarty (2000), Grollman (1995) and Kalish (1980) agree that dying children tend to display wisdom and understanding far advanced from what we would normally expect. According to Knapp (1986) as death approaches there is usually no hysterical outbursts, no agitation, no hostility rather calmness seems to overtake the dying individual along with the sense of revered wisdom and maturity. Such changes have been noted in children as young as three years of age. "Children below five usually view death as reversible, a departure or separation. Children from about six to nine or ten conceptualize death as an inevitable external process, which most often results from the action of the other individuals or purposes forces e.g. God and serves as punishment for evil thoughts or deeds. Children above ten begin to view

as an internal process inherent and universal in all forms of life including the self” (Kalish, 1980, p. 35).

While young children may not understand the permanence of death young children do react to loss. Changes in the emotional atmosphere of the house and the response of significant other may upset their secure world. During elementary years they begin to understand that death is final. Around the age of ten children usually begin to recognize that as universal and inevitable experience that will occur to them (Grollman, 1995).

Bowlby (1969) proposes a preventative measure as well as a precursor to a child’s experience of loss and its successful resolution. He posits that the proximity to the attachment figure provides the child with a safe haven from threat; the accessibility of the attachment figure provides a secure base from which a child might more confidently confront challenge, and separation from the attachment figure triggered separation anxiety. Hence, it can be deduced from this that while the loss of a major attachment figure in childhood can and usually is devastating the presence of other substitute attachment figures or the presence of the securely attachment primary attachment figure can facilitate the bereavement process in children. In the event of the child losing a sibling, survivor guilt is also an issue (Bigelow, in Infeld and Penner, 1996). If the death followed a long illness it could possibly mean that the deceased child’s siblings are likely to have endured months of neglect (Grollman, 1995).

While adults are not comfortable dealing with children's sadness especially when they are grieving themselves (Grollman, 1995), it is comforting to know that dying children are able to reach a sense of completeness prior to death, even if it is not expressed in adult terms (Bertoia, 1993).

Religion and spirituality in the grieving process

The death of child ultimately tends to change the religious orientation of the parents/caregivers in a positive direction (Grollman, 1995; Kavanaugh, 1974; Knapp, 1986). A belief in a higher power appears to provide comfort for the grieving parent (Knapp, 1986), allowing the opportunity to entertain the notion of being re-united someday with their beloved child. Consequently, no grieving situation can be considered without taking into account the attitude of the bereaved person towards his or her own eventual death (Kalish, 1980) as well as their individual repertoire of coping strategies (Grollman, 1995). "The more confused or ambivalent a parent is to the meaning of death, the good nature of God and the existence of a life after death, the greater the delay, the longer grief work is delayed the more difficult it is to do it effectively" (Kalish, 1980, p.155).

HIV/AIDS and Bereavement

The exploration of HIV/AIDS on the bereavement process is a fundamental aspect of this study. The diagnosis of AIDS has profound implications for the patient. The prediction of death that most make in conjunction with diagnosis, the chilling realisation that no cure yet exists and that friends are dying of AIDS, and the widely unsympathetic response of the public to affected homosexuals, generates a sense of

entrapment for most patients, especially in the first few months following the news (Miller, Weber and Green, 1986).

Most individuals view HIV infection as a death sentence. According to Bartlett and Finkbeiner (2001) most people react to learning of their diagnosis of HIV infection with confusion, shock and disbelief. People with HIV infection often have profound feelings of grief about the losses they have experienced or are anticipating. They grieve for themselves and those who must stay behind and try to cope with life without them (Van Dyk, 2001). They begin to have problems with eating and sleeping; they blame themselves, are frightened, depressed, sad, agitated, and anxious and become entirely preoccupied with the diagnosis. In anticipation of rejection from others, they may isolate themselves. These responses can last from a few weeks to a few months but typically lasts around six weeks (Bartlett and Finkbeiner, 2001).

In relation to children, studies show that vertical or perinatal infection is the major route by which children acquire the virus and the prevalence in children reflects the rising prevalence in women (Goldman, 1994). Children with HIV infection may develop a wide spectrum of signs and symptoms, including opportunistic infections, encephalopathy, failure to thrive, recurrent bacterial infections, malignancy, and LIP. Most infected children have a number of coexisting illnesses and may be receiving treatment for acute infections at the same time a prophylaxis and treatment for persistent infections (Goldman, 1994).

HIV/AIDS presents some special issues, different from other chronic life-threatening illnesses. Some of these are because of its nature, that is, it is an unpredictable illness with a wide spectrum of clinical problems, some of which are very uncommon. Differences also occur because HIV is a family disease with more than one family member affected. Goldman (1994) claims that even paediatric staff used to working with the chronically ill have rarely had to deal with the possibility of concurrent illness and the death of the child, and his mother, father, and siblings. Not surprisingly, AIDS increases the number of widows and widowers. When parents/caregivers die, children are often left in the care of grandparents and/or other members of the extended family or community (Weiss, Adler and Rowland-Jones, 2001).

Children may be symptom-free for an unpredictable length of time. Developmental delay and regression can be anticipated but not predicted. The child may be dying, then improve, and go on to live for weeks, months or even years. As a result, parents/caregivers may have to go through anticipatory mourning and come to accept the loss, only to have the child recover leaving the family bewildered (Goldman, 1994). Hence, anticipatory grief plays a large part in the grieving process of HIV/AIDS sufferers (Bartlett and Finkbeiner, 2001).

HIV/AIDS also posits the possibility of many attachments being severed at the same time because of the means by which the virus is passed on from person to person and the consequences of infection. The entire family can be infected resulting in multiple deaths within the intimate family system. The needs of affected others are

similar to those experienced by the HIV-infected person. These needs are acceptance, respect, certainty, affiliation, support, love and caring (Van Dyk, 2001). Hence, the process of bereavement is understandably similar for those who are dying and those who are forced to witness death (Van Dyk, 2001).

The situation is compounded by feelings of isolation due to the social stigma of being HIV positive and facing the fear of ones own impending death. The presence of a social support network has been considered to be an important moderating variable in stress-illness relationships (Kurstak, Lipowski and Morozov, 1987). In light of HIV/AIDS, according to Miller et al (1986) patients suggest that they have become a “social leper” and will avoid discussing their diagnosis with others for fear of the anticipated response occurring. This fear of rejection results in feelings of isolation which prevents the formation of new attachments, which is the point, in relation to the resolution of grief, where one is said to have accepted the death and ‘moved-on’ with ones life (Warden, 1982; 1991). Such a scenario prolongs the bereavement process. Hence, few AIDS sufferers reach a state of verbalised acceptance of death (Miller et al, 1986). These complications contribute to a significant increase on the emotional burden placed upon the individual.

AIDS appears to increase mortality rates in adult age groups that typically have the lowest mortality rates (Weiss, Adler and Rowland-Jones, 2001). According to Weiss, Adler and Rowland-Jones (2001), by 1997 the proportion with one or both parents dead had risen to 7% in many African countries, and rose to 11% in some. Mother-to-child transmission, which is estimated to occur, in the absence of

interventions, in about 30% of births to infected mothers, accounts for increased infant and child mortality (Weiss, Adler and Rowland-Jones, 2001). These researchers claim that in South Africa the number of perinatally infected HIV positive cases in 2001 were approximately 75000 per year.

Affected others suffer in many ways as a result of untimely deaths. People who die of AIDS are usually young (between 25 and 35 years), and this leads to the “unnatural” situation where parents/caregivers outlive their children. Grandparents who are contemplating a quiet and contented old age now often find themselves forced to nurse and care for sick and dying children as well as grandchildren (Van Dyk, 2001). In some instances, the community or extended family may care for the orphaned children (Goldman, 1994). Weiss, Adler and Rowland-Jones (2001) in a study of HIV positive children aged 0-12 years, conducted at King Edward VIII Hospital, cite that 40% of the children studied lived with their biological parents, 50% with extended family, 5% were adopted and 5% were in foster care. Fear of stigma may lead parents/caregivers to lie to family and friends about the diagnosis. This may once again lead to isolation, lack of support and sympathy and guilt if the child dies, possibly resulting in depression and thoughts of suicide for the grieving parents/caregivers (Goldman, 1994).

An interesting development in the processing of the diagnosis of HIV infection is the belief in witchcraft being responsible for HIV infection helps make sense of the horrors and disruptions caused by HIV/AIDS (Van Dyk, 2001). According to Van Dyk (2001) witchcraft is believed to be the causal agent in HIV

transmission, AIDS and death in many African countries, especially among the rural poor or people with the least education. He goes on to say that blaming sorcerers and witches for AIDS, serves to console both family, victims and society as a whole by projecting responsibility on eternal factors. In addition, it fits in with African worldview thus helping alleviate feelings of guilt and anxiety (Van Dyk, 2001), as attributing HIV infection to witchcraft may also help the bereaved family to avoid feeling stigmatised by their community (Van Dyk, 2001).

A young child may be the first member of a family to present with signs or symptoms, which may be due to HIV infection. The issue of testing the child then broadens to include, by implication, also testing the mother and other family members. During the course of the disease, any family member may be ill, dying, or bereaved simultaneously. Often they will be at different stages of coping with their illness and bereavement (Goldman, 1994). Parental/caregiver bereavement is unlike other forms of bereavement (Rando, 1986) and carries a higher risk of pathology (Goldman, 1994). "Many of the patients seen fall into well known suicide risk groups- they are facing recent traumas (diagnosis), many are very depressed, they may have endured the loss of a loved one, they may be living alone and socially isolated, they may have declining physical health and they may be suffering recently imposed financial hardships" (Miller, Weber and Green, 1986, p.148). These pathological bereavement reactions occur more commonly when the loss is sudden, unexpected, untimely, or horrific, when there have been deaths preceding or following, and where social support is lacking (Parkes, 1985). Unfortunately, another unique parental reaction to the loss of a child is to wish for a replacement child (Cain and Cain, 1964;

in Goldman, 1994). This is unlikely to be a viable option for most HIV positive parents/caregivers due to the risk of infection to the new child. High rates of morbidity after the death of the child are more likely when there has been pre-bereavement psychological ill health, and this correlates with the length of the illness prior to death (Rando, 1993).

Studies of neuropsychological testing in AIDS patients early in the course of the illness confirms the clinical impression that there is often early cognitive compromise in AIDS patients, even in those who are in the least symptomatic phase of the illness (Kurstak, Lipowski and Morozov, 1987). Common mood and behavioural problems in AIDS patients include agitation, depression and grief, apathy, socially inappropriate behaviour, hallucinations, delusions, anxiety, and memory impairment (Kurstak, Lipowski and Morozov, 1987). Psychological factors play a significant role in that they do not affect the primary infection but rather, the duration and severity of the illness are modified by psychosocial factors (Kurstak, Lipowski and Morozov, 1987). Hence, neuropsychological factors are likely to negatively influence the progress and duration of the bereavement process.

Children are more likely than adults to develop pathological mourning reactions (Goldman, 1994). The problem is compounded by the fact that children are largely excluded from the counselling process in Africa because (among other reasons) caregivers often simply do not know how to talk to children (Van Dyk, 2001). Consequently, children are less likely to acquire the psychological support necessary for successful resolution of their individual bereavement response.

The natural history of HIV infection in children differs from that of adults. The period from infection to illness, in the absence of effective treatment is 7.5-10 years (Weiss, Adler and Rowland-Jones, 2001). The observation that infants are more vulnerable than adults to HIV disease is beyond dispute. Recent data from a cohort in Malawi appear to indicate an even more dismal prognosis for perinatally infected children in parts of Sub-Saharan Africa, with 89% mortality by 3 years of age (Weiss, Adler and Rowland-Jones, 2001). In addition, perinatally infected children generally progress to disease more rapidly than infected adults (Weiss, Adler and Rowland-Jones, 2001).

Approximately a quarter with vertically acquired HIV infection develop severe disease in the first year of life. The remainder have a more slowly progressive course and the progression to AIDS is much slower. Retrospective studies suggest the age at diagnosis and presenting symptoms influence prognosis. Children under one year of age with opportunistic infections or HIV encephalopathy had a poorer survival than those presenting later with bacterial infections or lymphocytic interstitial pneumonitis (LIP) (Goldman, 1994). The lack of psychological support for children results in the impact on the under 5 mortality rate being more severe, as many infected infants will live beyond their first birthdays but few will survive beyond their fifth. The actual effects could be larger if children who are orphaned when their mothers die receive worse care than other children (Weiss, Adler and Rowland-Jones, 2001, p.78). Hence, social support appears to be a crucial factor in the progression of HIV infection. Consequently, rapid progression of the disease is likely to result in death

sooner for those children who receive inadequate care compared to those that are better cared for by their parents/caregivers.

Conclusion

Bereavement for the loss of a person important to us is a psychological process in which we engage according to our attitudes. Like other attitudes we have, our attitudes about death and bereavement are not innate. They are taught to us by our culture (Grollman, 1995). The death of a child is a very traumatic experience that manifests in lifelong implications for the grieving parents/caregivers (Bertoia, 1993). While the grieving process is a means of resolving and assimilating the loss of the child, individual responses to the grief process are moderated by social expectations and parameters (Grollman, 1995; Kalish, 1980 and Knapp, 1986).

Men and women react differently to the grieving process, which is likely to result in marital discord (Kaplan, 1971; Kalish, 1980; Knapp, 1986). In addition, the grieving process appears to be affected by the nature of the death (Grollman, 1995; Kavanaugh, 1974; Knapp, 1986), by the attachment style between the child and the parents/caregivers (Becvar, 2001), by the individual's psychological reaction to the grief (Kalish, 1980) and by the social response that he or she receives (Brown, 1999; Fogarty, 2000; Grollman, 1995; Kalish, 1980; Knapp, 1986). Other factors that affect the grieving process are the individual's religious orientation and their level of spirituality (Grollman, 1995; Kavanaugh, 1974; Knapp, 1986). Freud (1950 & 1957), from a psychoanalytical perspective talks about the bereavement process being a

means of withdrawal of energy from the deceased and the re-investing of this energy into another object.

In addition to the parents/caregivers struggling with feelings of anticipating the death and hope that their dying child will recover, the dying child needs time to prepare for his or her impending death (Knapp, 1986). When the death of the loved one is HIV/AIDS related an additional burden is placed on the parents/caregivers. Hence, the diagnosis of HIV/AIDS impacts on the grieving process of sufferers (Bartlett and Finkbeiner, 2001) and their families.

Consequently, while we do have much literature on the grieving process in general and we do acknowledge that HIV/AIDS makes a significant impact on the grieving process of sufferers, we are still unable to pinpoint the distinction between the bereavement processes of individual's who have lost a child to HIV/AIDS and those who have lost a child to a cause other than HIV/AIDS. Allowing these distinctions, if any, to emerge will enhance the understanding of the grieving process of HIV/AIDS sufferers and their families. Hence, the rationale for this study is grounded in the implications of bereavement due to HIV/AIDS for the surviving parents/caregivers. In the next chapter, the rationale and methodology will be explored.

Chapter 3

Methodology

Rationale for the study

Theoretical models of mourning and conceptual descriptions of grief have been explored in the literature review. The notion that there are specific steps, tasks or stages in the grieving process has been largely explored and reiterated by researchers such as Dane and Miller (1992), Kavanaugh (1974) and Worden (1982). Alexandra and Adlerstein (1958, in Grollman, 1995) and Knapp (1986) discuss individual responses to grief and the variance in grief response. Knapp (1986) specifically mentions “the personality structure of the individual” are influenced by “the social factors that are at work within the individual, by the importance of the deceased in the life system of the individual and by the value structure of the individual” while Alexandra et al (1958) refer to their contention that “death has a greater significance for people with less stable ego self pictures than for people with an adequate concept of self”. Brown (1993) and Grollman (1995) explore the social support and environmental circumstances of grieving individuals and document the processes they utilize in managing their grieving response.

However, although much is known about the grieving process, not as much is known about mourning the death of a child. We are especially interested in the comparison of grieving for children who have died of HIV/AIDS compared to other causes of death. This is especially because of the stigmatised nature of HIV/AIDS, and the possible discrimination against the families of children who might be thought to have died of AIDS.

As mentioned in the introduction chapter, this study is set against the background of a high prevalence rate of HIV infection in South Africa, which includes the infection of children. Due to the high prevalence of HIV parents/caregivers face multiple deaths in the community (Bartlett and Finkbeiner, 2001). These high mortality rates include the death of children to HIV/AIDS. However, the question can be raised whether deaths from HIV/AIDS impacts on the grieving process in any particular way. Given the highly stigmatised nature of HIV/AIDS, one might expect considerable impact on the grieving process e.g. through impacting on the availability of support structures within the sufferers' immediate environment (Brown, 1993), or discrimination against families with AIDS related deaths. It is the aim of this study to examine the grieving process in the parents/caregivers of deceased children, and to compare the grieving process in the parents of children who have died of AIDS as compared with other causes of death.

While much research has been done on the grieving process, research on bereavement due to HIV/AIDS appears to be less extensive. The manner in which an individual copes with the bereavement process impacts on their loved ones (Grollman, 1995). Many programs in South Africa are attempting to support people dealing with HIV related experiences for example, pre-test and post-test counselling is made available for individuals who request an HIV/AIDS test (Lovelife, 2001). Hence, further investigations into the impact of HIV/AIDS on the grieving process of the family of an HIV/AIDS victim will help us better understand and manage the grieving process of these families.

Aim

The aim of this study was to develop an in-depth understanding of parental/caregivers experiences of grief and bereavement in response to the death of their child or children. A specific sub-aim of this study was to compare the parental/caregiver experiences of grief and bereavement due to HIV/AIDS and non-HIV/AIDS related causes of death.

Design

Given the concern with in-depth understanding of the experience of grieving, a qualitative design was chosen. Mouton (1998) wrote that a descriptive design includes data, facts, empirical generalizations, narratives and stories, and provides truthful descriptions of phenomena in the world. This study was interested in individuals within their own diverse social and cultural context, and a qualitative design seemed well suited to this (Holloway and Wheeler, 1996).

The Qualitative Approach

Researchers have focused on different aspects of qualitative approach. Thomas (1990) described the qualitative approach as “consisting of information derived from communication or observation of behaviour. It focuses on human perception, beliefs, attitude, and experience of participants” (p.18). Munhall (1998) has cited Benoliel (1984) describing the qualitative approach as “ modes of systematic inquiry concerned with understanding human beings and the nature of their transaction with themselves and with their surroundings” (Munhall, 1998, p 27). Wilson (1985) described the qualitative approach as “a science of distinct modes of inquiry oriented

towards understanding the unique nature of human thoughts, behaviours, negotiations and institutions under the different sets of historical and environmental circumstances” (Wilson, 1985, p.59). However, Parker (1994) describes qualitative research succinctly when he describes qualitative research as “the interpretative study of a specific issue or problem in which the researcher is central to the sense that is made” (p. 2). Hence, the emphasis in qualitative research is to develop a greater and more valid understanding of human behaviour and experience.

In this study the aim was to gather information that directly represents the parents/caregivers experience and beliefs. Strauss and Corbin (1994) described qualitative research, as any type of research that delivers findings not arrived at by statistical procedures or other means of quantification. In-depth interviews were chosen, as this mode of data-collection seemed best suited to the broad aims of this study.

Grounded theory

Grounded theory (Glaser and Strauss, 1974) was used as the methodological framework for this study as the researcher did not want to superimpose a pre-existing theoretical framework upon the datasets. While studying dying patients, approximately 50 years ago, Glaser and Strauss used a methodology that focused on the emergence of theory rather than the verification of existing theory (Glaser and Strauss, 1967). The research method utilised was coined “Grounded Theory Methodology” (Freirherr v. Manteuffel, 2005, p. 3).

Grounded theory is a method of qualitative research that utilizes comparative analysis as a tool to discover theory emerging from data sources with four central criteria, i.e. a category they call work (generality), relevance (understanding), fit (valid), and modifiability (control) (Freirherr v. Manteuffel, 2005). It was decided to use Grounded theory in this study because this methodology was initially developed with the aim of generating theory inductively and moved away from deductive research and the verification model. Hence, this study aims to explore the difference between bereavement due to HIV/AIDS and bereavement due to other causes of death by generating theory.

Ultimately, the grounded theorist's task is to develop a theory that accounts for much of the relevant behavior or experience (Glaser and Strauss, 1974). Consequently, the strongest case for the use of grounded theory is in the investigation of relatively un-chartered water (Freirherr von Manteuffel, 2005).

Grounded theory is a means of developing theory during the actual research and it does this through continuous interplay between analysis and data collection (Strauss and Corbin, 1994, p.46). Grounded theory meets two major criteria of a good scientific inductive theory, namely parsimony and scope. Parsimony refers to a heuristic, which states that if two theories are equally tenable, the simpler one is to be preferred (Reber, 1988), while scope refers to the reporting of as much variation in behaviour in the action scene with as few categories and properties as possible. The creativity required in accomplishing this task is to generate categories and properties through constant comparison of incidents and concepts and to aptly name them so

others will feel their grab (Glaser, 1992). The researcher concurs with Glaser's (1992) belief that the researcher doing grounded theory should allow the theory to emerge as he/she observes codes and analyses data.

The researcher in grounded theory does not think up hypothesis with the aim of testing them but rather looks for patterns of relationships. Verification is not ruled out but rather can come later, as part of a later verification study. According to Glaser and Strauss (1974) "evidence and testing never destroy a theory; they only modify it, hence, a theory's only replacement is a better theory" (p. 28). Consequently, accurate description and verification are not so crucial when one's purpose is to generate theory (Glaser and Strauss, 1974). The researcher agrees with the belief that when the main emphasis is on verifying the theory there is no provision for discovering new theory. Hence, emerging data that contradicts the emerging theory may be discarded or suppressed (Glaser and Strauss, 1974). However, "when generation of theory is the goal, one is constantly alert to emerging perspectives that help and develop the resulting theory" (Glaser and Strauss, 1974, p 40).

Comparative analysis puts a high emphasis on theory as process, that is, theory as an ever-developing entity, not as a perfect product – hence, it is still developing (Glaser and Strauss, 1974). Once again, then, generating theory is spoilt when not considered the main goal of the research by focusing more on accurate evidence and verified hypothesis.

Interestingly, Glaser himself is reported not to have used transcription (H. Van Rooyen, Personal communication, August 2003). Consequently, during this study the first interview was transcribed. And the transcript and field notes were analysed before going on to the next interview or observation.

Method

Sampling method

Qualitative study requires in depth investigation of the subjects' individual reality. Hence, although it is advised that one sample to the point of redundancy for the purpose of producing quality research, ten sets of bereaved parents/caregivers appeared to be an adequate sample size for the purpose of this study.

Purposeful sampling was employed. In this sampling method, the selection of units is based on a previously specified purpose (Halloway and Wheeler, 1996). Burns and Groves (1997, p. 366) wrote "it involves the conscious selection by the researcher of certain subjects or elements to include in the study". The sample comprised of parents/caregivers of deceased children. The qualitative approach necessitates in-depth analysis of data. Hence, the researcher approached the parents/caregivers of ten deceased children for interviews.

Strauss and Corbin (1990) describe three kinds of sampling; open sampling linked to open coding, relational and variational sampling linked to axial coding and discriminate sampling which they link to selective coding. The researcher is interested in the incident, event or action, how or why is it different from or the same as other incidents, events or action and how or what, if any, links one event, incident or action

to another. The freedom to compare any group that satisfies the criterion of theoretical relevance used for each comparison in systematically generating theory, controls data collection without hindering it. Control by this criterion assures that ample data will be collected and that the data collection makes sense. However applied theoretical control over choice of comparison groups is more difficult than simply collecting data from a preplanned set of groups, since choice requires continuous thought analysis and search (Glaser and Strauss, 1974). Hence, according to the above process, the possibility of multiple comparison groups are endless, therefore, the researcher chose groups according to theoretical criteria (Glaser and Strauss, 1967). Once a parents/caregivers had died, these children were placed in foster care or lived with a grandparent. The research subjects comprised of parents, grandparents and foster parents of deceased children. The targeting of primary caregiver rather than parent was the key criteria for participation in the study. Hence the sample was composed of bereaved primary caregivers of deceased children. This diversity between different caregivers within the sample emerged as a result of purposeful and snowball sampling techniques. In this study diversity was attained including deaths due to HIV and non-HIV related causes, diverse causes of non-HIV related deaths, and various types of parent or caregivers, including foster mothers, and grandmothers and the inclusion of a parent/s who had lost multiple children.

The participants comprised of ten sets of English speaking, bereaved parents/caregivers of deceased children aged from infancy to early adulthood. English was a second language for only one of the two black, isiZulu speaking participants. It was decided for the study that the participants would be limited to ten sets of

parents/caregivers. Since emergence of theory is the aim of the grounded theorist, and this study utilized Grounded Theory, the kind of evidence, as well as the number of cases, is not crucial. For example, a single case can indicate a general conceptual category or property; a few more cases can confirm the indication (Glaser and Strauss, 1974). Therefore, it is their contention that “in research catered for discovering theory the researcher cannot site the number and types of groups from which he collected data until the research is completed” (Glaser and Strauss, 1974, p 50). The emergent theory points to the next steps, which are unknown until gaps emerge in the theory and until previous answers suggest research questions (Glaser and Strauss, 1967) because grounded theorists use categories drawn from respondents themselves, which cannot reliably be preconceived and tend to focus on making implicit belief systems explicit (Borgatti, 1998).

There were six mothers and two fathers, ranging in age from thirty-six years to sixty-four years. Six of the parents/caregivers shared a home while two were divorced, separated or lived apart due to economic reasons. One was a single parent that either lived alone or lived with extended family. Five of the deceased infants, children or young adolescents lived apart from either parent and three of those five deceased individuals lived apart from both their biological parents. Two of the participants were foster care mothers or fathers and one was a grandparent of the deceased child. One mother had lost two children to asthma attacks and the grandmother had lost her son, her daughter-in-law and her grandson to HIV/AIDS. One of the fathers had lost multiple family members to HIV/AIDS and one of the foster mothers had previously lost a foster child to HIV/AIDS.

Table 1: Characteristics of parents/caregivers

Parental information:							Deceased information:		
	<u>Parent/ caregiver</u> <u>M/F</u> <u>(Race)</u>	<u>Spouse</u> <u>Present</u>	<u>Age</u>	<u>Marital</u> <u>Status</u> <u>(Length</u> <u>of</u> <u>marriage)</u>	<u>No. Of</u> <u>Children</u> <u>(Including</u> <u>deceased)</u>	<u>Time</u> <u>Elapsed</u> <u>Since</u> <u>death/s</u>	<u>Gender,</u> <u>Age and</u> <u>Relationship</u> <u>to parent/ Caregiver</u>	<u>Cause of</u> <u>death</u>	<u>HIV</u> <u>status</u>
1	Female (White)	✗	37 yrs	Married (19 yrs)	2	2 yrs	Male (15 yrs) -Son	Cancer	✗
2	Female (Black)	✗	36 yrs	Single Parent	4	2 yrs	Female (2 and a half yrs) -Daughter	Asthma	✗
						2 yrs 4 months	Female (5 yrs) -Daughter	Asthma	✗
3	Female (Indian)	✓	40 yrs	Married (17 yrs)	2	9 months	Female (15 yrs) -Daughter	Cancer	✗
		Male (Indian)	42 yrs				-Daughter		
4	Female	✗	43	Married	3	+/- 5	Female	Cancer	✗

	(Indian)		yrs	(24 yrs)		months	(18 yrs)		
							-Daughter		
5	Female (Collared)	✘	39 yrs	Married (18 yrs)	3(+1 foster child)	2 and a half yrs	Male (11 yrs) -Foster child	Pneumonia	✓
6	Female (White)	✘	57 yrs	Married (10 yrs)	2	15 yrs	Female (18 yrs) -Daughter	Car accident	✘
7	Female (Indian)	✘	64 yrs	Married (45 yrs)	6(+2 grand - Children)	1 and a half yrs	Male (12 yrs) -Grandson	Pneumonia	✓
8	Male (Black)	✘	47 yrs	Married (18 yrs)	4	1 yr	Male (20 yrs) -Son	Pneumonia	✓
9	Female (Collared)	✘	41 yrs	Married (19 yrs)	3	8 months	Male (5 yrs) -Son	Pneumonia	✓
10	Female (Colored)	✘	59 yrs	Widowed (40 yrs)	4 (+3 foster children)	2 yrs	Female (8 months) -Foster child	Heart failure	✓

Key: M/F= male or female

Yes = ✓

No = ✕

Procedure

Parents/caregivers were recruited with the help of the social worker at the Highway Hospice. Lists of terminally ill children who were initially referred to the Hospice by other agencies or individuals or next of kin of deceased children were screened by the social worker for suitability i.e. they had to be recently bereaved parents/caregivers of deceased children, very briefly introduced to the study and permission acquired for the researcher to approach them about participating in the study. Initially, the study was restricted to children who had died at the Hospice and their bereaved family that had contact directly or indirectly with the Highway Hospice. However, as the study progressed, difficulty in acquiring participants from the hospice due to availability resulted in the recruitment of parents/caregivers via leads acquired from previously interviewed parents/caregivers. Lack of availability of suitable participant acquisition may have compromised the scope of the study.

The researcher received the names and telephone numbers of the prospective parents/caregivers after the social worker at the Highway Hospice had acquired permission from the parents/caregivers for the researcher to contact them regarding an interview. The researcher contacted the parents/caregivers telephonically. The purpose of the telephonic interaction was to explain the purpose of the study and to obtain consent again from the prospective parents/caregivers to participate in the study. Once the parents/caregivers had agreed to the interview, a time, date and venue

was decided upon. The parents/caregivers were then included on the bases of verbal consent to participate in the study after receiving an explanation about the study from the researcher. The researcher either met the parents/caregivers at the parents/caregiver's home or at the Highway Hospice, depending on the preference of the parents/caregivers. A single interview was carried out. The length of the interview ranged from an hour and a half to three hours, depending on there being a single parents/caregivers or both parents/caregivers present.

The study did not require that the parents/caregivers be interviewed as a couple. Rather the decision was informally left to the parents/caregivers. The parents/caregivers were invited to participate in the research and a time was negotiated for the interview. It was up to each individual parents/caregivers to decide if he or she would like to be present at the interview.

The Interview

The researcher introduced herself, explained the purpose and implications of the study briefly to the parents/caregivers and then asked the parents/caregivers for some demographic information (see appendix 1). The researcher filled out a demographical questionnaire for each of the parents/caregivers. This questionnaire comprised of questions such as their age, gender, marital status and number of children. Single parents/caregivers families were not excluded. Thereafter, semi-structured interviews were carried out with (both) parents/caregivers (see appendix for details).

The parents/caregivers was then asked about his or her experience of the bereavement in relation to the death of their child. The researcher invited the parents/caregivers to talk about his or her experience by saying to the parents/caregivers, "I am interested in your experience of bereavement. What has helped you and what has not? What you have found difficult and what you have not found difficult?" The parents/caregiver was then allowed to talk freely about their experience. The researcher only utilised the interview guide when necessary, for example, when a parent/caregiver continued to say the same thing over and over, or when elaboration was necessary. Hence, the interview guide was used to prompt or probe the parents/caregivers.

The questions, probes and prompts were written in the form of a flexible interview guide and the written questions were not put to the parents/caregivers directly but rather incorporated into the natural flow of the conversation. Hence, sequencing of questions was not the same for all the parents/caregivers, as interviews were allowed to follow its individual process (Holloway and Wheeler, 1996). Flexibility in relation to interview style was an integral part of the research design. Miller and Crabtree (1997) describe the semi-structured interview as a guided, concentrated, focused and open-ended communication of events that are co-created by the researcher and the interviewees and occur outside the stream of everyday life. Consequently, the researcher found it necessary to oscillate between an open-ended and semi-structured approach to the interview.

Parents/caregivers were allowed to speak at their own pace, in their own time. Consequently, the flow, quality and volume of information shared by the parents/caregivers differed from individual to individual. In addition, the level of prompting and guidance provided by the researcher facilitating the interview differed between the different parents/caregivers. At the end of the interview, parents/caregivers were invited to mention any addition information, emotions or comments that may have arose during the interview or that the parents/caregivers felt needed to be heard or was not explored during the interview.

The researcher developed an interview guide early in the study (Appendix I). This interview guide was developed so as to assist the interviewer in exploring relevant areas of interest. However, as the interviews progressed, the interviewer found it beneficial to allow the interview guide to gently guide the interview process. The researcher found it necessary to do this due to bereavement, the grieving parents/caregivers appeared to be distractible and sometimes vague in their responses.

The interview attempted to cover parents/caregiver's beliefs and perceptions of HIV/AIDS, level of communication between the parents/caregivers, level of and exposure to outside support and facilitation such as friends and family, government agencies, educational institutes, professional associations and legal services, and perceptions of personal accessibility to these support mechanisms; as well as the level of perception and acceptance of the child's HIV status. For instance, do they perceive the death to be HIV/AIDS related and what does that mean to them?

Data analysis

Analysis of the data followed the broad principles of Grounded Theory. Grounded theory emphasizes the concept of emergent data. Glaser (1992) believes that the researcher doing Grounded Theory should allow the theory to emerge as he or she observes codes and analyses data. In order to fulfil this requirement, the researcher followed a three step coding process based on Grounded Theory (Glaser and Strauss, 1967; Kock, 2002; Strauss and Corbin, 1990) including open coding, axial coding and selective coding (Kock, 2002).

Open coding involved labelling phenomena found in the text. As is consistent with Grounded Theory, the researcher read or listened to each line with the question in mind “what is this about? What is being referenced here?” (Borgatti, 1998). Memos were written as the process unfolded and observations of the researcher noted during the interviews. As the interviews progressed, the researcher tried to maintain a constant interplay between the emergent data and datasets identified during preceding interviews. Once the researcher believed that the process of open coding was exhausted, selective coding began. According to Glaser (1992) selective coding means “to delimit coding to only those variables that relate to the core variable, in sufficient ways to be used in parsimonious theory” (p.75). The core variable in this study was bereavement. All codes identified relate to the core variable. Hence, selective coding is concerned with grouping together similar descriptions of experiences under one code rather than the development of new codes. For example, the descriptive words used by the parents/caregivers to describe a particular emotion such as depression, gloom and misery can be descriptive of a feeling of sadness or

grief. Hence, all these codes could be included under the code sadness or grief. The researcher then used axial coding in order to link together all the major codes in order to extrapolate underlying themes (Glaser, 1992).

The researcher developed or added a new code or theme to the dataset, if and when it emerged throughout the analytical process. The researcher believed that flexibility in allowing new codes to emerge all through the analytical process was important as codes should emerge from the data rather than be preconceived and then imposed on the data by the researcher. According to Glaser and Strauss (1974) having pre-conceived codes or limiting the emergence of new codes is not data generation but data selection (Glaser and Strauss, 1974). The researcher concurs with the above-mentioned statement. Hence, the researcher was careful in approaching the datasets without any preconceived or presumed codes. While coding is the identification and naming of emergent variables, analysis refers to the discovery or identification of over-riding patterns within the datasets that results in the development of conceptual frameworks and theory.

The type of codes and categories that should be generated from the analysis has according to Glaser and Strauss (1974) two, essential features. First, the themes should be analytic that is, producing theory that is conceptually and systematically understood and secondly, they should also be sensitizing that is, yield a subjectively meaningful picture that can be easily related to. With this in mind, eventually, according to Glaser (1992), with strict adherence to Grounded Theory methodology, a well-constructed theory will result that meets its four most central criteria to be

conceptually sound, to be functional, practically applicable or workable within the relevant context, to be beneficial within this context and to be modifiable when faced with new, relevant datasets.

Constant comparison.

The researcher used the process of constant comparison based on Grounded Theory to compare the reported bereavement processes of the parents/caregivers of the deceased HIV positive and non-HIV positive children using the codes developed. Constant comparison refers to the process of linking, exploring and questioning the similarities or differences between different parts of the datasets, in this case the parent/caregivers of children who died from HIV/AIDS and those who died of other causes.

Ethical considerations

The researcher approached the relevant institution/s by means of a letter inviting their participation in the study. The letter contained information on the study, the benefits of such a study being carried out and the precautions that the researcher was taking in order to safeguard the parents/caregivers and the institution itself. These precautions are elaborated on below. A representative was then appointed by the institution to assist in the acquisition of participants for the study. This representative contacted the bereaved parent/caregiver. The representative briefed the parents/caregivers on the purpose of the interview and asked permission for the researcher to contact him or her for an interview. Once permission was granted, the

researcher contacted the parents/caregivers and set up a suitable time and venue for the interview.

The researcher introduced herself clearly by stating her name, credentials, course of study and the name of the university that she attended. Parents/caregivers were invited to participate in the study, and were encouraged to exercise their right to terminate participation if they should wish to at any stage of the process. They were introduced to the nature and purpose of the study. The parents/caregivers were also informed before the interview about the nature of the task, what would be required of them and the potential risks and threats inherent in their participation. The parents/caregivers were advised about the anticipated length of the interview, the kind of information the interview was likely to explore and the possible emotional responses that such an interview might elicit.

Permission was requested from the parents/caregivers to tape-record the session. Parents/caregivers were assured that the tape-recordings were for research purposes only, was confidential, would be made available only to the researcher and the relevant supervisor, would be stored in a safe place and would be disposed off safely once the study was completed.

The parents/caregivers were assured that all data would be confidential, that tape recordings and written data did not make mention of the parents/caregivers names and that these records would be safely stored inspected only by the researcher and the researchers supervisor. The subjects were provided with relevant telephone

numbers in case they needed to contact the researcher at a later stage and were invited to contact the researcher at any time after the interview if they needed in order to address any residual psychological or emotional after effects of the interviews.

The parents/caregivers were advised at the outset that any individual who did not want to participate could decline to participate. The researcher answered any questions posed by the parent/caregiver fully and honestly. The parent/caregiver was given enough time to consider the information and to seek clarity before making a decision. The parents/caregivers were informed about confidentiality and were then once again invited, if they so chose, to continue with the interview.

All efforts were made to ensure that the parents/caregivers were treated with respect in that they were not interviewed under duress and were treated with respect and compassion, and that any requests made by the parents/caregivers were treated in a fair and just manner at all times during the interview. At the end of the study the researcher debriefed the parents/caregivers and answered any questions they may have had. The researcher assured the parents/caregivers that after the study all records would be safely disposed off. The parents/caregivers were free to contact the researcher anytime after the interview in order to help manage uncomfortable feelings or emotions that may have arose as a result of the interview.

Chapter 4

Results

Introduction

The results obtained in this study suggest that bereavement is a social, rather than individual event. It appears that a key indicator of successful resolution of grief in an individual is the social environment within which that person finds him or herself. Common themes emerged as the analysis progressed. Themes comprised of a collection of smaller components referred to as codes. Hence, a number of codes emerged from these themes. These codes help describe and clarify the themes.

Key demographics of participants

<u>Subject</u>	<u>Gender</u>	<u>Age</u>	<u>Marital status</u>	<u>Length of marriage</u>	<u>Number of children (Including deceased)</u>
1.	F	37	Married	19 years	2
2.	F	36	Single	-	4
3.	F	40	Married	17 years	2
	M	42			
4.	F	43	Married	24 years	3
5.	F	39	Married	18 years	3 + 1 foster child

6.	F	57	Married	10 years	2
7.	F	64	Married	45 years	6+ 2 grandchildren
8.	M	47	Married	18 years	4
9.	F	41	Married	19 years	3
10.	F	59	Divorced	40 years	4 + 3 foster children

Themes

Grieving as coping alone

Parents/caregivers unanimously voiced the importance of a supportive network of friends and family in relation to the grieving process. All parents/caregivers claimed to have experienced some of isolation and some feeling of being misunderstood by others. For some feelings of isolation appeared to play a significant part in their grieving response while others claimed that misunderstandings between themselves, their significant others and the community resulted in a lack of support that hindered the resolution of grief.

Isolation

Four of the parents/caregivers make reference to emotional isolation even though they claim to have access to adequate social support while seven

parents/caregivers claimed to be receiving adequate support. In relation to the grieving process perceived feelings of isolation were reported to have impacted negatively on individual experiences of the grieving process. This point is clearly reiterated in the words of the parents/caregivers of a deceased HIV positive child when she says that the “Last thing you want is to be alone, makes you think too much doing things to keep going takes a lot out of you”. In addition, the level of support offered by others may not be adequate to the needs of the bereaved parents/caregivers. Hence, another mother says, “...my husband tried. You know and from my family I did, I got a lot of support, but they weren’t with me, to help me, you know, cope”. Feelings of grief appeared to be overwhelming and resulted in many instances in inadequate communication of misunderstandings. These lapses in communication then appeared to result in isolation for the bereaved. The mother of an accident victim describes her experience of this when she says, “You’re not aware of it in the beginning...of how blunt you can be and then slowly you begin to see the reactions of other people”.

Misunderstanding

Four of the seven parents/caregivers made reference to feeling misunderstood by others, including their spouses. Parent/caregivers tended to reiterate the point that “Individuals mourn in their own way”, as, mentioned above. Parents/caregivers went on to say that this individual mourning experience resulted in misunderstandings between themselves and their family. The mother of a young cancer victim tearfully quotes what she would like to say out loud to friends and family, “I am hurting inside. You cannot see so you should be the last to talk because you didn’t experience it”.

This mother felt misunderstood and judged by her community. In addition to this she felt that there was a distinct difference in the manner in which different cultures managed the grieving process. Her impression of her own cultural experience is summed up clearly when she exclaims “That is one thing about Indians I can’t tolerate- so judgemental”.

Fluctuations in grieving

All the parents/caregivers reported that they experience fluctuations in the grieving process. According to many of the parents/caregivers interviewed, some days are better than others, and special days such as birthdays, religious celebrations and family functions appear to renew the feelings of loss and sadness. As one mother stated, “You get your good days, you get your not-so-great days”.

Shock/ disbelief

Although five parents/caregivers claim to have experienced feelings of shock or disbelief at the time of the death, all parents/caregivers report experiencing feelings of shock and disbelief at some time during the grieving process. “ It was a very big shock, it was. And suddenly you thought, okay, chemo would help...unfortunately that wasn’t the case, you know”, a mother whose son died in her arms as she rushed for help states “ It was a shock because he died in my hand. I was carrying him to the clinic. At the time when I was carrying him he was already dead...I don’t know what happened. My brains were dead or what or I was confused”.

Furthermore, feelings of shock and disbelief appeared to resonate in feelings of emptiness within the parents/caregivers. The mother of a teenage cancer victim said, “ You miss someone so much. He was with you, now all of a sudden he’s gone...” and the mother of a teenage accident victim says, “It was a very painful time. Initially it was so painful because there was suddenly this emptiness that couldn’t be filled though we were expecting her to die...for weeks inside me was just...terrible. I just wanted to see her for the last time just to say tell me something (crying)...and then as the days went by...it is so difficult, some days it’s easy some days it’s painful. Some days I just cry I can’t avoid crying”. Hence, feelings of shock and disbelief appear to eventually fade away as the bereaved parents/caregivers begins to accept the permanence of the loss. As a result, it appears that an acceptance of the loss is likely to eventually result in the uncovering of an inexplicable void within the bereaved individual that yearns to be filled.

Guilt

Two parents/caregivers reported feelings of guilt towards the death. Feelings of guilt tended to resolve over time, as this mother states “(I was) angry with myself. I blamed myself for not...after a while I thought no, nothing could have been done...and I think I realized that it was not my fault. And after that I started to feel a little better, now I am not so frustrated”. For other religious belief seemed to alleviate feelings of guilt, “I think she is in the better place now. I miss her a lot and I have no regret that I didn’t do anything because as the parents/caregivers I did everything that I could. There is nothing that I left out that I should have done because I did everything, her medical, her clothes, holidays, the toys everything (crying)”.

Parents/caregivers complained of the insensitivity of others in inducing feelings of guilt “ I am here today, you don’t know if I am going to be here tomorrow so I will enjoy my day today...family is very supportive but others make me feel guilty”. In addition, guilt feelings were experienced in relation to whether they believed that they were grieving in the ‘right’ manner or whether external feedback supported their personal bereavement process. For instance the mother of a deceased teenage girl wondered, “My first husband, he questioned why it wasn’t him and I often wonder I never questioned why it wasn’t me...I just don’t know why I never questioned why I hadn’t died”. In the last month before her daughter’s death when she was bedridden the mother of a deceased teenager, claimed “I was hoping for her to die because I felt now there was no turning back in the state she was.... felt inside that that was such a cruel thought”.

Hope

Seven of the parents/caregivers claimed to have hope that their child would recover from the illness, “No, I had so much faith that a miracle could happen and it would...I wouldn’t believe a thing, not a thing” and another “Had so much of hope...told everyone I met she would get better”.

It is interesting to note that these seven parents/caregivers experienced feelings of hope even though their doctors explicitly informed them that the prognosis was poor or that there was no hope for survival. Many of the parents/caregivers stated that doctors had told them explicitly about the chances of survival for their child but in

spit of this they held on to the hope that their child would beat the illness. For instance, “when I made an appointment with doctor he had made it clear to use that it was difficult cancer to treat and if she survived it will be a miracle...”.

It may be interesting to investigate the relationship between hope and denial at this stage or to explore hope and the outcome perceived or hoped for by the parents/caregivers. Some parents/caregivers claim that they hoped that the child would recover completely while others hoped that their child would recover from the relapse this time, as he or she had done so many times before, without any allusion to the future progression of the cancer in their child.

It seems that when denial is eradicated, hope seemed to die. For instance some parents/caregivers acknowledged the death of hope once the physical condition of the child had deteriorated, “that was the most...in fact the last month when she was...I was hoping for her to die because I realized there was no turning back from the state that she was”. Another grieving mother reiterates this point, “ She suffered too much, ...told God to take her away”. Parents/caregivers appear to be willing to let go of their feelings of hope that their child will survive so long as they believe it to be beneficial to their child. Hence, a loving parents/caregivers was likely to sacrifice his or her need to keep the child alive for the sake of the child’s comfort, that is, to end the child’s suffering and pain.

The mother of a child who had died at the scene of an accident reported feelings of hopelessness and helplessness. There was no room for hope in this

scenario resulting in extreme outbursts of anger, “I got very angry when Tamlyn died. I never swore, never any swearing and now I swore like a...since she died. I still swear not to the extent I did at that time but ah my daughter and I we actually said the “f” word um a lot like at the funeral she was crying, crying and I said something...but I don’t um I was extremely angry”. This extreme angry response accentuates the notion that feelings of hope allow for the slow and controlled progression from denial to acceptance. Without hope, uncontrolled anger is released, and as with anything uncontrolled the consequences could be far reaching and the damages permanent.

Anger

Six of the parents/caregivers claim to have experienced anger at the death of the child and currently still experience these feelings from time to time. Parents/caregivers experienced many forms of anger. They reported anger at the experience of grief, “ Ja, you get angry with yourself because all you are doing is not working...you put all this frustration and anger onto another person...help...you know what I mean”. They reported feelings of anger because it had happened to them and not someone else, “You know it’s something I don’t want to actually look back on. It was traumatic, really traumatic. And I don’t wish any parent to go through something like that” or “I’ve lost three years of my life and you want me to lose more”. They projected anger upon other family members, “...there was a bit of anger though not because Terrence gave up and died the anger it was more towards me and the majority of the anger was towards my husband for not sort of being there for me and helping me”. Parents/caregivers reported anger at God and the struggle between anger and the denial of anger, “Me, I’m a Christian, and the majority of the emotional

stage I'm never angry, I never blame anyone, because I knew it wasn't my will. But emotionally I think it was somebody else's will". And lastly, they directed anger outwards towards an external object, resulting in indiscriminate anger that appeared to find a target at random, "So that's what happened. She died on the scene. There were lots of doctors around Umphlanga Rocks drive and they resuscitated her and then we went to Addington. I don't know why Addington, there was no Umphlanga Rocks Hospital during those days and that was it. Just ask questions on what you need to know, because what you're doing, I understand what you're doing, you're confirming the emotions I had at the time but you know it is a shock, you know what I am saying. Can you not just ask me what questions you need, if it's not going to ruin your little survey"?

One mother expressed anger at what she believed to be the lack of purpose in a child living if not only to leave so soon. This mother became bereaved fifteen years ago when her daughter passed away in a motorbike accident. In this mother's case, it appears that holding on to the anger is a means of holding on to her daughter, and in so doing keeping her child alive, if not physically but spiritually.

The findings of this study suggest that each new stage of bereavement is likely to be met with some measure of anger from the bereaved. Hence, unresolved anger appears to stagnate the bereavement process, resulting in an unresolved grief process that can manifest indefinitely.

Denial

All parents/caregivers admitted to experiencing feelings of denial. They expressed these feelings of denial in comments such as “I wouldn’t believe it there was no way it was going to be” and “ I had so much faith that a miracle could happen and it would...I wouldn’t believe a thing, not a thing”. Two parents/caregivers report continued feelings of denial towards the death of their child. Both of the above-mentioned parents/caregivers were experiencing great difficulty in the resolution of their grief response.

Denial at the time of diagnosis appeared to be a common response in the non-HIV/AIDS parents/caregivers, for instance the mother of a teenage cancer victim said, “ she said to me...it is very rare in children but she didn’t want to tell me the actual truth because I wouldn’t accept anything at that stage”. This denial of or disbelief in the impending death of their child coupled with feelings of hope seemed to propel these parents/caregivers into a frenzy of activity, each parent looking for any means by which they could save their child. Most of the parents/caregivers claim to have clung to the hope that their child would survive, that their child would be the exception to the rule, or that they would be blessed by a miracle. When this did not happen, denial seemed to transform into a need to lay blame. The mother of a teenage cancer victim accentuates this struggle between need for control over the situation and acceptance of feelings of powerlessness over the inevitability of death. She says in relation to the testing of her two other children for a match with their ailing sister’s bone marrow, “I think doctors found when they did the tests that she was too far gone and they just told us that they (two siblings) were not a match”.

The HIV parents/caregivers, in contrast, appeared to be overcome by feelings of doom. Minimal feelings of denial and the lack of hope for a recovery were significant in this group. A grieving grandmother spoke of advice given to her in regard to HIV positive grandchild by his doctors before he died, "Christy's doctors said that we should give him whatever he wanted (because) it won't take long (for him to die), and we did". It appeared that parents/caregivers had from the outset accepted the loss of their loved one. Hence, parents/caregivers were able to get closure in most instances before the death of their loved one. The greatest concern for these parents/caregivers was not the death itself but the kind of death. For example, "I am grateful that it was quick and over. The death was not painful". The foster mother of a HIV/AIDS victim claimed to be "Relieved for him when he died". Hence, many of the parents/caregivers of HIV positive children mentioned that they were either pleased that the child had died painlessly or were still traumatized by the painful death suffered by their loved one. The foster mother of an HIV positive infant with full-blown AIDS said, "She had five major heart attacks...very painful death" and claims to be angry with HIV. She claims that as a result of the trauma of the death she now has angina.

Parents/caregivers appear to manage the denial of the death of a loved one in two opposing ways after the death of the child. This phenomena was play out overtly in the control of the immediate environment of the bereaved and the management of material possessions of the deceased. In the first scenario, the parents/caregivers seems to deny very strong feelings by hurriedly packing away unresolved issues and

removing any reminders of such. For instance the foster mother of a teenage HIV/AIDS victim says that it “Helps to get rid of all his stuff quickly...gave clothing away quickly that helped and the other things are in the cupboard... not in the way”. In the second scenario, the parents/caregivers tended to hold on to the physical environment of the deceased, almost as if the fact that the child’s room was exactly as he or she had left it, his possessions were exactly where he liked them to be, a place was set for him or her at special occasions or a the table would somehow re-establish his or her existence. For instance, one mother whose son died two years before described how she scolded her other son for disturbing the deceased’s bedroom or allowed only controlled access to his possessions even though the surviving son “shared” the bedroom with the deceased and had a need for the use of some of his deceased siblings possessions, she says, “I am very protective, not protective. I don’t know how to put it...(I say) don’t lose it...put it down, something like that, once you finish wearing it. Then I’ll put it away...the clothes, I can’t put it away...his room must not be touched, everything is as it was when he died”, this same mother claims that “I buy him (surviving child) a lot of extra things even at Christmas as well, you know, I feel like something from Terence (deceased) to give to Tyrone and it makes me feel good”.

Expression of grief

Three parents/caregivers mention that they cried a lot at the time of the death. For instance, the mother of a teenage cancer victim feels the need to justify the expression of sadness in the form of crying by saying “He was with you, now all of a sudden he’s gone...so basically you feel quite tearful”. Cultural issues seemed to

impact on the manifestation of grief in the form of crying, rather than for example praying, “My mother stopped me. You know in our culture. They say if you cry something happens to that person. I remember one day my mother’s sister they were dreaming about my baby. My baby was crying and crying and crying and he was naked. My mother said to me, you see stop crying because you are disturbing you baby and he is not happy. They said he can’t go through because you are crying because of you tears “uyakhala nje” they are stopping him” and “ In our culture, you know when my mother gave me a hug I didn’t cry and when she told me I must pray to God”.

Three parents/caregivers claim to have not cried at the time of death but rather at a later stage. The mother of two children who died from asthma attacks recounts her experience of the day of one of her children’s funeral, “So I just went to my room, I don’t know what happened that day I lost my brains, cleaned my wardrobe, packed my clothes and cleaned the room and mattress. I took the curtains down and hanged it where I had to. People who come to cry for me...I don’t know what happened that day” but after the initial shock wore off she says that “I keep on crying and crying if I saw the children playing because they used to play together”.

Anticipatory Grief

Some parents/caregivers reported that the anticipation of death seemed to prolong the suffering of the parents/caregivers, perpetuating feelings of loss, helplessness and hopelessness. The grieving father of a teenage cancer victim said that “We knew from the outset that she would not survive” and were told by the

doctors that if she “survived it would be a miracle”. In his words, he emphasizes, “To live with someone who is dying is worse than if someone died in a accident because you have to live with it because your healing starts immediately”. Hence, anticipatory grief did not seem to minimize the reaction to the death as strong feelings of denial, anger and guilt were still obvious in parents/caregivers of the cancer victims as mentioned earlier, or help in the successful resolution of grief as the parents/caregivers of the cancer victims were still looking for closure over the death of their child, as described by this grieving mother “it was a very painful time. Initially it was so painful because there was suddenly this emptiness that couldn’t be filled though we were expecting her to die...I just wanted to see her for the last time just to say, tell me something...”.

Role of religious belief in the grieving process

Many of the parents/caregivers reported that their religious beliefs brought them solace and relief from their grief. Eight of the parents/caregivers claim to be religious. All eight parents/caregivers claim to have become even more religious after the death of their child. The foster mother of an infant HIV victim states that she had “Always been religious but I communicate more often with God now because I need it”. Hence, questions evoked by the death were satisfactorily addressed by their religious belief system. Strong religious belief appeared to elicit a sense of peace and acceptance on the part of the believer. The father of a teenage cancer victim’ responds to his wife’s discomfort regarding their daughter’s death by saying, “...Best way to go, when she hasn’t committed any sins. Your life has to go on, her faith was to go”.

Just as the allegiance to a particular belief system is likely to assist the grieving process, the lack of religious belief or atheism was reported to hinder the grieving process. Three of the parents/caregivers claim to have lost or diminished faith in God after the death of their child. The mother of a teenage accident victim says in relation to losing faith in God, "...um, I lost faith my faith when she died".

It appears that the parents/caregivers who lacked faith previously or had lost faith in a God were having a more difficult time in coming to terms with the death than those who were religious previously or who had not lost faith because religion perpetuates the belief in the afterlife. Hence, one grieving mother explained the belief in the afterlife succinctly when she said, "knowing that one day I will see him, and we will be together...our religion...that helps".

In addition, those parents/caregivers who had become more religious after the death reported to be coping better than those who were previously lacked a belief in God, those who had lost faith and those who had maintained their level of belief in a higher power. The mother of a teenage cancer victim talks about their management of grief, "Best way to handle death is... prayer helps the best...only God can give us comfort, always with you. I was not very religious but because of the death I have turned more to prayer", she goes on to say, "My husband was not very close to God, only now".

In relation to religious teachings, lack of control, or rather handing control over to God, is perceived as good. In this way, parents/caregivers were able to admit a

lack of control in a manner that was acceptable to themselves as well as to those around them. In addition, they felt comfortable handing control over to an entity that they believed to be trustworthy as well as an entity that they believed to be always working for the greater good for all concerned. For instance, the mother of a teenage cancer victim said, "Me, I'm a Christian, and the majority of the emotional stage I'm never angry, I never blame anyone, because I knew it wasn't my will. But emotionally I think it was somebody else's will" and another mother says, "I don't know how can I advice. But you can't do anything because we all forget. If God is comes to take that person you can't stop him because God lend us this person and he comes to take him again, we all forget. We can't stop God. Another thing they must pray for the person who was suffering because we can say if like something is burning me like a fire and another person can only sympathize but cannot feel what feel. It's only me how I feel like".

While other parents/caregivers question God, "I asked myself a question, how could God do this to me at the same year in between two months this thing happens to me? Maybe I had done something wrong or I was doing something wrong", this questioning appeared to come from a deep disappointment in God rather than a disbelief in God. Hence, it appeared that a strong religious belief system shaken by the death of the loved one appeared to illicit reproach responses such as the above in the parents/caregivers, rather than a complete denial or disbelief in their particular religious belief system.

Differing views on religion appears to affect communication between family members. This is especially evident when faced with religious belief and atheism within the same family system. A mother painfully accounts how her teenage daughter confided in her aunt rather than herself about a conversation she had with God before she died, “Krishna came to fetch me and you know what I told him. I need three more days and then I’ll come”. The mother goes on to say that her daughter passed away three days later. As a result, this particular mother is very unhappy over the fact that the child never spoke to her openly about how she felt about dying. The daughter was well aware of the mother’s ambivalence over religious issues. A lack of a religious belief has left the mother confused and afraid. She struggles with questions that remain unanswered without a religious system such as “where did she go?” and “Is she safe and happy?”. The mother says, “I wish there were some answers”. She ponders over questions such as, “Where is heaven? What is heaven? Where is she? What has happened to her? Does she remember us or does she want to be with us?” The confusion is apparent in that she at one instance will say something like “I haven’t seen God” and then at another instance will say something to the contrary such as “Used to pray to God that if she died she must die remembering us and not slip into a coma and that is what happened”.

Consequently, differences in religious belief between role players as well as the lack of a religious belief system appears to result in a lack of communication or misunderstandings between family members. As stated earlier, a lack of communication as well as misunderstanding between role players was reported to hinder the grieving process. Hence, the findings of this study suggest that differences

in religious belief systems between significant role players, hinders the grieving process.

As religious belief systems address questions about the well being of the loved one after he or she has passed on a lack of belief in religion leaves many important questions regarding the well being of the deceased loved one remain unanswered. Hence, in addition, this study also finds that a lack of belief in religion or atheism results in a more severe grieving response.

Focus on the future

Seven of the eleven parents/caregivers had plans that focused on the future. Some parents/caregivers focused on the future as a means of distracting themselves from the pain they felt in the present. The mother of two children who had died from an asthma attack said, “You know when I’m thinking about them I ...I forget by thinking about the future. For instance, if I am to buy a new house I will and think about the plans and forget about (them)...” while the mother of a five-year-old HIV/AIDS victim finds solace in the arms of her infant grandchild who she claims ‘helps us heal’. To her it feels as if her infant grandson has taken the place of her deceased son, so she says that whenever she longs for her son she reaches out to her grandson. In this way, it appears that she is focusing her efforts on nurturing and developing her relationship with her grandson. Consequently, by focusing her efforts on the future well being of her grandchild she appears to be inevitably shifting her focus from the sorrow and grief of the present to the possibilities of the future.

Parents/caregivers who had been involved in prolonged treatment programs, which took up much of their time, appeared to be lost and confused once the death had occurred. The mother of a teenage cancer victim who received treatment for three years during which she had had her leg amputated and numerous minor operations and procedures said, "It was a long process. For these three years our lives just revolved around her. We didn't know the weeks, the years the months that was just passing by, you know, because our focus was her and we moved into the area we bought the house and things like that and we couldn't continue because of her illness we just stopped we thought we should rather keep the money for her medication and things like that. So, then the last month she became very, very sick because this cancer was moving, moving to her private area and then she had her leg amputated". This grieving mother's desire to focus on future plans and activities that she believed would bring her joy and fulfillment could only be justified, it appeared in her mind, if off-set against the suffering she endured during her daughter's illness. While she felt that the only means by which she could resolve her grief was by participating in behaviors and activities that nurtured and fed her spirit she also believed that the community shunned her efforts. Hence, this resulted in her continually reiterating the trauma they experienced during the illness and their legitimate claim to "moving on".

The two above mentioned examples not only illustrating the means by which parents/caregivers attempt to move on after the death of a child but also highlight the impact that a socially acceptable or a socially unacceptable course of action can have on the grieving response of the parents/caregivers.

In this study, a further two parents/caregivers claimed to be able to cope with the “present” moment only and were surviving on a “day-to-day” basis, both these parents/caregivers were experiencing significant distress in their grief responses. One of these parents/caregivers, the mother of a teenage cancer victim highlights the struggle between being caught between feeling no future and pressuring one self to live, when she says, “ These days when you can’t just carry on. You know, and you’ve actually got to get the courage to carry on”.

Social Environment

The social environment within which an individual finds him or herself appears to play a significant part in the grieving process. In this study, reports by the parents/caregivers suggest that the social environment was greatly impacted upon by individual’s ability to seek out help, and to offer help to those in need. In addition, the individual’s ability to seek out help or to offer assistance was greatly impacted upon by cultural issues, social pressures and restraints and the social support available to the bereaved individual.

Counselling or help seeking behaviour

Parents/caregivers acknowledge the importance of therapy to cope with the grief, as a foster mother of an infant HIV victim said, “The best way to handle it is by talking, group therapy...” However, most parents/caregivers echo the same message that is that social support is more important than counseling in the grieving process. The mother of a teenage cancer victim stated that “...Terence did belong to CHOC,

they don't help as such, well I've had about two calls." Three parents/caregivers made reference to the importance of counseling in the resolution of grief. Two of these three parents/caregivers had been for pre and post bereavement counseling. The parents/caregivers who had had this counseling found it helpful, "A lot of pain, a lot of counseling, helped a lot before she died...had family, individual, couple".

One parents/caregivers declined counseling even though her doctor recommended it for her. She claimed that counseling did not affect the resolution of grief significantly. Other parents/caregivers reported that adequate social support might help alleviate the need for counseling. Reports by parents/caregivers suggest that individuals viewed the availability of counseling as one of many means of acquiring social support, if or when needed. The mother of another teenage cancer victim claimed that when she needed support she sought help from the "Social worker and my mother if I've got problems".

Parents/caregivers of these deceased children reported that they gained solace and strength from parents/caregivers around them such as doctors and nurses who knew their child on a personal basis. For instance, the mother of a teenage cancer victim said that the "Oncology department (people) were very compassionate. Riona had an impact on everyone...all called". Other parents/caregivers found solace and comfort in learning how to counsel others effectively as well as providing counseling to others who face the same or similar dilemma. One parents/caregivers stated "I did the Lifeline course and I counseled for nine years with Lifeline so I know really what

I shouldn't do, I know those kind of things but I choose not to and you know I carry on".

Altruistic behaviour

Six parents/caregivers claimed to be involved in some form of altruistic behavior such as volunteer work, support and counseling for the bereaved and general charity work. The mother of a teenage cancer victim states, " (I) feel I can talk to people who are going through the same thing".

Those parents/caregivers who performed altruistic behaviors reported coping better with their bereavement better than those who did not participate in altruistic behaviors. As the foster mother of a teenage HIV/AIDS victim said "After Kegan another family lost a child to AIDS...brings up all the feelings but I was able to encourage and help them. It helped to help others, being there for someone else, not the only one...".

Cultural issues

Four of the parents/caregivers reported experiencing social problems due to the social pressure to conform to prescriptive cultural practices for grieving such as rituals. Four parents/caregivers experienced an above average level of assistance and comfort from the practice of certain rituals, which included practical methods of praying.

The mother of two asthma victims recounts how she was told of the death of her children. When her first son passed away she recounts, “After a while my sister came through and gave me a nice smile as if nothing has happened...But my sister did not want to tell me that my baby was gone...I asked what happened they say no nothing is wrong the baby is fine...My sister said come, they want you” and at the time of her second sons death, “They didn’t phone me. They didn’t do anything...they just all their eyes they looked at me like this (make big eyes) as if something happened...so when I got there I saw the blanket and when I looked at the blanket there was nothing...My mother just hugged me again and she said God will bless you...She said I couldn’t do anything...She said that we should just pray because we can’t do anything. I agreed with her”. She claims that cultural practice dictates the manner in which death is managed in the black community. In relation to her cousin dying she says, “ We heard the sound of my fathers car. We wondered why he had come so late at night. My mother asked him what happened and he said nothing. He said I just came to take something I’m in a hurry. In actual fact she had died”. In all three counts, the death remains concealed from the primary loved ones as a means, it appears, of protecting him or her from the grief for as long as possible.

According to the mother of a teenage cancer victim, as a member of the Indian community, she found that she was crowded and overwhelmed by others resulting in her needs and possibly that of her child being neglected. She says, “you know the only problem with us Indians when we have a crisis situation as much as we appreciate everybody caring I felt the last few days I needed some quality time with

my child (crying) that I did not get- at least a few hours”. Hence, rather than supported, protected and cared for, she felt abused and neglected.

Social attitudes, pressures and restraints

Five parents/caregivers complained of social attitudes that hindered or complicated their individual experience of the grieving process. Parent/caregivers reported that social expectations played a key role in the manner in which individuals managed their sick children as well as how they behaved after the death. The mother of a young HIV/AIDS victim said, “ I knew something had happened because he was sick when I left him but I didn’t tell anybody here at work because sometimes I don’t want to tell the people all the times, oh! Today my baby is sick! I don’t know how people feel like because not all people are the same. Some of them they agree with you and some of them don’t agree with you, they think you don’t want to come to work”.

In this study, pressure to conform to socially accepted cultural characteristics was reported to play a significant role in the experience and manifestation of the grief response. This is illustrated well by the mother of a teenage cancer victim when she recalls the night her daughter died, “When I had gone into the room she had already passed away. I feel hurt because I wasn’t there...the only problem with us Indians, when we have a crisis situation, as much as we appreciate everybody caring. I felt that the last few days I needed some quality time with my child that I did not get- at least a few hours”. In another instance, this same mother says, “But I find among the Indian community people are ready to point fingers. If I want to go to a party there is nothing

wrong with that. I have a life to lead and I need to go out because I heard people say, oh but her daughter just died and she is going to umpteen parties”.

In some instance, the bereaved seemed to interpret socially acceptable means of grieving as a burden or pressure to conform to socially acceptable means of grieving. One mother noted, in relation to other friends who have also lost a child, “I found out...that all of us don’t know what’s the right thing to do...anything you do is alright. It doesn’t matter. People were asking me – I open the curtains in my child’s room in the morning and I close them at night, is that all right? We used to do this, and I still do that...for years I didn’t think I was doing it properly”. Social prescriptions are likely to assist in this instance guiding an individual towards socially accepted means of expression. In conforming to social prescription, an individual is likely to gain acceptance and support from his or her community. Hence, one parents/caregivers implied that social prescriptions proved to be helpful in the grieving process.

Social support

Descriptions by parents/caregivers suggest that emotional and social support from family appeared to improve the mood of bereaved parents/caregivers. The mother of a teenage cancer victim said of her mother, “ She was there for me, she didn’t show any emotional state. She was very supportive, and it sort of picked me up a bit”. In addition, the support of family members appeared to help the bereaved cope better, “ ...more supportive towards me showing more love and affection towards me knowing what I was going through JA so that I would be stronger”.

The mother of the two children who died of asthma attacks admits that people tended to assist those that were bereaved in her community, “Sometimes they bring food to help because they know you used your money for doctors or hospitals and the funeral arrangements after the death” but also attributes negative connotations to some people within her community “Some of them are happy that a person dies”. Hence, there does appear to be some ambiguity in relation to the offering of assistance as well as the willingness to accept assistance within her community.

Conflict is likely to arise when the perceptions of close family members differ in regard to what to do when bereaved or in mourning. To this the mother of a teenage accident victim says, “whatever you feel is right for you. There is no right, there is no wrong...um...some people never come out, some people carry on as normal- at least they look normal...there’s no books written on what you going to feel. They can write books and they can tell you you’re going to go through all these processes but it is more than that and its something that is specific to each individual”.

Family relationships

Marital relationship and the grieving experience

Three of the eleven parents/caregivers reported strained or poor marital relationships. Problems within the marriage that preceded the death appeared to become more evident after the death. The mother of a teenage cancer victim said in relation to her husband’s grief, “My husband...can’t really say it was this or it was that. Even to this day he hasn’t really grieved... and it’s hard to really talk to him”,

and the mother of a teenage accident victim said regarding her emotional needs at the time of the death, "I had plenty of support...um...what I didn't have was...really...like having been divorced, it's difficult".

The quality of the marital relationship appeared to play a significant role in the resolution of grief. Poor marital relationships tended to place the deceased, especially if first born, into the role of confidant. The mother of a teenage cancer victim who treated her deceased son as her confidant while he was alive went on to say of her emotionally unavailable husband after her son's death, "(if he) was more supportive towards me showing more love and affection towards me knowing what I was going through. Ja! So that I could be stronger". This scenario appeared to manifest in enmeshed relationships between one of the parents and the deceased then resulting in a complicated grief response.

In addition, the pre-death relationship between the deceased and each of his or her parents/caregivers appeared to impact on the resolution of each of the parents/caregiver's individual grief responses. The existence of an enmeshed relationship between one of the parents/caregivers and the child before the death appears to have resulted in emotional distance and estrangement between the spouses during the life of the child. This emotional distance and estrangement between the spouses is likely to translate into a lack of emotional support for one another after the death. This study finds emotional support between bereaved loved ones and parents/caregivers to be an important aspect of the resolution of the grief response.

Hence, the lack of emotional support, especially within the home environment, is likely to hinder the grieving process of bereaved parents/caregivers.

In addition, lack of communication between spouses did not appear to hinder the bereavement process if the personality of the spouses favored reclusive, introverted or very independent behavior or the dynamics of the marital relationship made allowance for the acquisition of emotional support outside the marital relationship, that is, from close family and friends. For instance, the father of a teenager HIV/AIDS victim was satisfied with the progress he had made in regard to his bereavement in spite of the lack of communication between himself and his wife in relation to the bereavement. The inability to confide in each other over the death could be largely attributed to the fact the teenager in question was a child from a previous relationship, that preceded the current marriage and that in the short time that the deceased had resided with the family his behavior had been rebellious and deviant in nature. This father claimed that he usually received emotional support from, “a friend...but don’t usually...keep a lot inside...have family available but keep to myself”, in addition, he feels unloved claiming that “no-one” truly loves him because “people are very materialistic”.

A good relationship between parents/caregivers appears to have a positive effect on bereavement responses. The parents/caregivers appear to work as a team, providing support for one another, maintaining a mutually beneficial relationship in relation to the grieving process. The mother of a teenage cancer victim talks about her supportive relationship with her husband, “Chantal was always very close to her

father...I was much stronger than him...He was not so close to God- only now (she is religious). It came as more of a shock to him..." she goes on to say that they communicate well with each other and have a good marital relationship which has remained fulfilling even after the death as they provide emotional support for one another. The foster mother of a teenage HIV/AIDS victim claimed that she felt loved by her husband and children, and was able to gain comfort and support from her husband but was also very concerned that "since he died my husband won't talk about it". It appears that in a loving and supportive relationship each of the spouses seems to keep a check on the progress of the other in the grieving process, noting areas of concern, voicing these concerns and helping their loved one resolve the issue. In addition, a good marital relationship allows for the expression of anger in relation to the death within a safe and supportive environment.

Enmeshed relationship with deceased and the grieving experience

It appeared as if there was a fine line between a normal relationship between the parent/caregiver and child and an enmeshed relationship. However, the presence of an enmeshed relationship with a deceased child appeared to culminate in greater distress in the grieving parents/caregivers.

Where parents/caregivers seemed more enmeshed with deceased children, the parent/caregiver emphasizes ownership when describing their child's physical appearance or lives. As a result feelings of "emptiness" when the child dies are likely to result in a desperate search for a substitute, which culminates in relational problems with surviving children. The mother of a fifteen-year- old cancer victim said, " He

was with me and all of a sudden he wasn't anymore. There's no one for me to say mommy this, or mommy that. I can't confide in him like a mother and son...I feel a little bit empty". The mother quoted above has a poor marital relationship with her husband and a surviving son who has Downs Syndrome. Consequently, she believes that she is unable to relate to them in the way she related to her deceased son. Furthermore, she believes that in order for her survive she needs him to "live" on. She is still in denial two years after he death, keeps his bedroom exactly as it was before the death, even with his younger brother having taken over the bedroom after the death and refuses to visit the grave sites as she believes that "he is not there".

The mother of a teenage cancer victim in comparing her surviving daughter and her deceased daughter said, "Stephanie looks like her father's side. Chantal was tall, everything like me". In addition, the above-mentioned mother appeared to be projecting her wish for the deceased daughter on to her surviving daughter as the surviving daughter is reported to have exclaimed on many occasions, "I am not Chantal" and "Don't compare me to Chantal".

Parents/caregivers in enmeshed relationships with their deceased children may attempt to continue this relationship in their management of special occasions. In this way the grief response is perpetuated rather than allowed the opportunity to be resolved for the parent as well as the surviving child. In relation to the surviving child and special occasions a mother said "Tyrone's birthday you know like an extra present but I buy him a lot of extra things even at Christmas as well you know I feel like something from Terence to give to Tyrone and it makes me feel good".

Relational problems with the child before death appeared to interfere with the processing, acceptance and assimilation of the death. The mother of a teenage cancer victim who claimed, “In fact we used to argue a lot” voiced frustration at the fact that while there appeared to be much interaction between herself and her daughter relevant information was not communicated effectively. The above-mentioned mother regretted time wasted on arguments and squabbles, stressing the importance of communication before the death. The mother of a deceased teenage girl emphasizes the importance of spending quality time communicating lovingly with the dying child when she says, “Give all the love, time, no regrets for later...” -a point that was reiterated by the other parents in the study. The father of an HIV/AIDS victim claimed to have experienced relational problems with his deceased child. He felt “very angry and frustrated” before the death of his son. He labeled his son as “very irresponsible with his life” and blamed this irresponsibility and the belief that he had “failed to teach” his son adequately as the reasons for him contracting the disease. This parents/caregiver’s relational problem with his deceased son did not minimize his feelings of loss. He claimed to “miss him a lot” and felt he need to “fill the gap”. In addition, it appears that relational problems with the deceased prior to the death impacted on the ability to converse comfortably about the deceased. The father of a teenage HIV/AIDS victim said of his son, “Miss him...hard thinking about him”.

The findings of the study suggest that the quality of relationship with remaining children has a strong impact on the grieving process. Nine parents/caregivers claim to have a good relationship with their surviving children. The

mother of a deceased cancer victim tries to include her surviving child in shared activities, “when I have spare time I say come lets do this lets do that” because she believes that “The time we lost with him because he was still a baby did lots of damage”. Parents/caregivers appeared to make a conscious effort to make up for lost time with the surviving children after the death. In this way, it appears that they were able to validate their parental/caregiver status which may have become shaken after the death of their child as well as appease uncomfortable feelings of guilt that may have arisen during the grief response.

The mother of two deceased asthma sufferers portraying a good relationship between herself and her surviving children, quotes the enquiries of one of her young surviving children, “ She said oh my mother how did Smanga left us here where is she going to because the time when we slept together you don’t know is she she’s walking without a dress...and maybe she is not dresses she is feeling cold. She kept on asking me a lot of questions, big, big questions”. And then later voicing her fears by saying, “oh mama, I’m so glad to hear that. After that after this one died she said, eh this one is going to that place again to do the same thing I’m frightened now maybe I’m also going. I said to her no it’s only the boys that will go there not the girls stop thinking about that. I told her she can’t leave me here only the boys should go there and we will meet one day and you will see them driving cars because they will make a lot of money”. Hence, while the above quote may not be acceptable example of good communication in Western culture, it is a response that is in accordance with Black cultural practice and highlights the importance of good communication between the caregivers and the surviving children. Good communication between the

parents/caregivers and the surviving children appeared to assist in the resolution of grief.

By contrast two parents/caregivers complained of emotional distance, inadequate interaction or lack of communication between themselves and their surviving child/children. The mother of a teenage cancer victim said in relation to problems with her surviving son, “ he didn’t want to go to school anymore because when Terence wasn’t well, at that stage we didn’t quite know it was cancer. He was kept out of school for a couple of months. He associated Terence and school to getting sick”. The mother of a deceased teenage cancer victim noted distinct relational problems with her surviving daughter who complains that she compares her to the deceased. She says of her surviving daughter, she “does not do anything” while her daughter, complains in relation to the comparison, that “I am not Chantal” and “ Don’t compare me to Chantal”. The mother goes on to say with a sense of pride “Everyone mistakes the name of my daughters, even now when they want to call Stephanie they say Chantal”. The mother of an accident victim says when explaining her relational difficulties with her surviving daughter, “...and sometimes children don’t want to upset their mothers by talking about what happened...” Hence, the lack of rapport between parents/caregivers and surviving children appeared to hinder the grieving process.

Routine and the grieving experience

Six of the parents/caregivers emphasized the importance of returning to their normal routine in helping to resolve their grief. Their child’s illness appeared to take

precedence in the home, resulting in a drastic change in routine for the rest of the family. Parents/caregivers reiterate the point made by the mother of a six year old HIV/AIDS victim when she says that she felt “Split between this child’s needs and the family and other children at home”. Parents/caregivers attributed these structural problems to the chronic illness of their child. Consequently, it appears that parents/caregivers and their family who returned to normal routine, that is the routine the family had before the illness and subsequent death of their child, soon after the death appeared to cope better than those who did not.

Regrets expressed by parents/caregivers

The findings of this study suggest that part of the grieving process appears to consist of coming to terms with regrets after the death of the child. Some of the parents mention regrets that they experienced after the death of their child. All the regrets expressed appear to center around having not given more love, time, and affection to the deceased. Hence, the general feeling was of having not given more or enough of oneself. One parents/caregivers, however, expressed her regret of having given too much of herself to her foster child who died from HIV/AIDS by having become ‘too attached’ to her. It is likely that this foster mothers response was reached on an intellectual rather than emotional level as she has had a great deal of exposure to literature, talks and workshops on the management of bereavement.

Many of the parents/caregivers expressed a dislike for chemotherapy, especially in the last stages of the child’s life. Their main objection to chemotherapy was the side effects and their impact on the last day so of their child’s life. In most

instances chemotherapy rendered their child unconscious or unable to talk due to mouth sores. This scenario hindered communication between the parent/caregiver and the child. The mother of a teenage cancer victim said, “Chemo makes them sicker- if we had known the last time that she was not going to get better we would have not sent her. At least she would have been able to talk nicely and tell us what she wanted, or where she wanted to go. We could have taken her”. Another mother reiterates this point by saying, “I wish that she did not have chemo (the last time) so that we could have talked with her in her last days”.

Communication about death and the dying process with the child appeared to be an important component of the grieving process for parents/caregivers. The foster mother of a deceased cancer victim said that she regrets not having asked more about the child’s feelings towards his mother as she knew that “he didn’t want to go by his (deceased) mother”.

The parents/caregivers voiced regrets over not having done something physically as the mother of a teenage accident victim mentioned, “I did not kiss Tamlyn when she died”, or the mother of a young HIV/AIDS victim said, “If I had given him the oxygen, he may not have died” and “He asked me not to go to work (the day he died) but I had to because I had missed a lot of work already”.

Parents/caregivers expressed regrets over not parenting better as the father of an HIV/AIDS victim said, “I wish I could have done better (with the deceased)”. Interestingly, the foster mother of an HIV/AIDS victim who passed away at eight

months of age claimed to regret having become too emotionally involved with the child. She felt that she had 'got too attached' to her foster child.

Ordinal position in grieving

Ordinal position of the deceased child appears to impact on the grieving process. When it was the first born who died, many of the parents/caregivers experienced significant feelings of deprivation, as if they were not able to receive or have their needs met anymore, while with a subsequent child it appeared as if the parents/caregivers felt an overwhelming need to give, but was unable to be received anymore.

The mother of a teenage cancer victim who was experiencing significant trouble in the grieving process said of the loss of her first born child "...with the first born you are very close to, you know, and Terrence and...I felt that (with) anything he could confide in me. He came to me for everything".

Exposure to loss- Multiple deaths and early death experiences

Nine of the eleven parents/caregivers had experienced multiple deaths of loved ones, friends, family and neighbors during their life span. The experience of multiple deaths reportedly assisted in the resolution of the grieving process. Exposure to multiple deaths appeared to have a positive effect on the resolution of the grief response.

It appears that exposure to multiple deaths allows one the opportunity to manage grief better due to experience of past successes in the resolution of grief. In addition, the management of multiple grief responses may lead one to prioritize certain activities or behaviors, which are likely to result in the speedy resolution of grief. For instance, the father of a teenage HIV/AIDS victim says that he believes his role within the family, and within the scope of HIV/AIDS bereavement within his extended family circle to be one of provider. In light of this he says, “the way people cope in urban areas is different from the traditional home” he goes on to explain that in the traditional home there is a lot of community support and the elders in the family take on the responsibility of taking care of the bereaved family financially. In his family, he is the eldest and also financially very secure hence, he provides financially for many of his extended families needs as many of his family members have died from HIV/AIDS. A grieving grandmother of the only surviving child of her deceased son after his, his wife’s and their young son’s death from HIV/AIDS, said, “Worry about my granddaughter now”. She goes on to say that her aim is to provide all she can to the best of her ability for her granddaughter as her sixteen year old granddaughter was the only one in the young family not infected with the AIDS virus. Hence, worry for the well-being of the surviving children seemed to include firstly, a concern for the child’s physical and psychological health and secondly, a concern for the dire consequences to the child if anything should happen to the parents/caregivers.

Of the eleven parents/caregivers interviewed, four of them had experienced the loss of a parent or sibling. Early or childhood experiences of death of significant others such as a parent appeared to have a positive effect on the resolution of grief. It

appears that loss of a loved one early in life, when a child does not have the responsibilities of adulthood to contend with allows an individual the opportunity to process and manage grief at a stage in life when they have the support and nurturance of an adult figure. Consequently, parents/caregivers reported coping well with their loss in their childhood. The perception of coping well with the loss is also likely to remain with the child as he or she grows into adulthood resulting in feelings of efficacy in regard to the loss of a loved one and the inevitable processes of grief and mourning. The mother of a teenage cancer victim recalls the loss of her father at the age of three. She claims that she experienced little emotional suffering as a result of his death as she was very young and had many older brothers and sisters to provide comfort if or when necessary. Her only strife was her mother's struggle due to a lack of finance. Overall, she claims to have had a happy childhood despite her father's demise.

There appeared to be no significant link between the time elapsed and the stage of grieving. Anticipatory grief experienced in the time between the diagnosis and the death did not appear to significantly reduce the time spent in each stage of the grieving process neither did it appear to reduce the existence of feelings of shock at the time of death.

Ability to converse adequately about deceased

The ability to converse freely about their deceased child appeared to be a marker in the successful resolution of the grief response. Nine parents/caregivers were able to converse adequately about their deceased children. Two parents/caregivers

were extremely uncomfortable as they found it difficult to talk about their children and showed feelings of hostility, anger and sadness. For instance, the mother of a teenage cancer victim said that she “Would like to be able to talk about Tamlyn with joy” but felt that she was unable to do so. She finds it hard to conceal her anger at having lost her child by saying that she feels that it is a waste for the child to have lived if they were just going to be taken away again. Hence, her attempts to find joy in the memories of her child appear to be hampered by the anger that she feels at her loss. The mother of an accident victim who at the time of the interview still appeared to be severely agitated by the death cannot talk comfortably about her deceased daughter fifteen years after the accident, “I don’t know...I feel a bit tearful, she had an accident. I knew this would happen, um feelings of loss. I don’t talk about her a lot um...its too sad”. Hence, time did not impact significantly on this mother’s ability to converse comfortably about her deceased daughter. Consequently, it appears that the inability to converse comfortably about ones deceased child does not appear to be a function of time as is the case with this mother but rather a measure of the resolution of grief.

The mother of a teenage cancer victim says about her attempts to find joy in her memories of her son, “It’s very seldom now but when I talk about it that’s when I get emotional. And...like last night for instance, I found a little card that he made in hospital as well, and he wrote in the card: “mommy I’m so sick”. However, she finds it easier to talk about her son in the presence of her mother. In light of this she says, “Terrence was always with my mom. We talk about all the happy times we had”.

Hence, parents/caregivers appear to find it easier to talk about their child comfortably with certain individuals.

The mother of two infants who died from asthma attacks says of a conversation with her young nephew, "My sister's baby used to call Smanga by his name because they were the same age. He will say, I miss him now and she will say I saw him in the coffin. What is he doing in the coffin I want him back...I always cry if I hear that, even the name..." However, at other times she is able to enjoy talking about her children, "...especially when it is special time because we use to pray together as a family. Like Christmas, like Easter because we use to pray together we make like a party and we talk about things we use to do...so we used to talk about that when we were together. So we think he was doing this and was doing that. Oh, I remember that one she was this and that. So we think about all the things they used to do".

Hearing others mention their deceased child in a positive light appeared to provide a covert or vicarious means of conversing about their child. It appeared as if vulnerable parents/caregivers of deceased children were able, in a sense by proxy, to converse safely about their child just by listening to others say good things about them. Parents/caregivers took great pleasure in these conversations and used the citation of these conversations as a means of talking about their child to others. For instance, the mother of a teenage cancer victim talks about her daughter and the impact she had on others, "Feel good when people talk about her, few years she had she made an impact on everyone".

Comparison of HIV/AIDS deaths and Non-HIV/AIDS deaths

The findings of this study suggest that there are significant differences in the experience of bereavement due to HIV and bereavement due to non-HIV related deaths. In addition, the findings of this study also suggest a relationship between the perceptions of the community, friends and family concerning the cause of death and the freedom of expression of grief in the surviving family of the deceased.

In relation to the significant differences in experience described by parents/caregivers in the resolution of grief in relation to HIV and non-HIV related deaths, two themes emerged from the data. The two themes are social support and religious belief.

It is important to note that all parents/caregivers interviewed reported the above two themes to be of vital importance in the resolution of their personal grief response. Hence, the distinction between the experiences of HIV and non-HIV related victims appears to be in the experience of grief within these specific arenas rather than in a lack of consensus concerning the importance and relevance of these two areas, that is social support and religious belief.

Two themes emerged from the data that appeared to reflect the perceptions of the community, friends and family and the expression of grief in the parents/caregivers in regard to HIV and non-HIV related deaths. The two themes are, firstly, the responsibility and culpability attributed to HIV infected individuals and,

secondly, the cultural prescriptions that dictate socially acceptable and socially unacceptable behaviour.

Social support and stigma and its effects on HIV and non-HIV related deaths

According to parents/caregivers reports, in relation to HIV/AIDS and non-HIV/AIDS related deaths, social support appeared to play a significant role in the resolution of grief. Unfortunately, in relation to HIV/AIDS social support appeared to be lacking due to cultural and social stigma. A Black mother said in relation to the death of her HIV positive cousin, “We are not the same some of them they just run away from the person. You know for some other people if they know that this person has AIDS don’t want to look at her or him like this (makes eyes big). They just run away”. In addition, she goes on to say, “ You know the people, they say you know you are my neighbour and I can help you but if I get there to help I might also get AIDS”. It therefore appears that while there may be an inclination towards helping their ‘neighbour’, individuals may find it difficult to follow through on such inclinations. It is likely that these inclinations appear to be easily over ridden because of ridicule and criticism hurled at HIV victims by society, and which can be attributed to stigma attached to HIV infected individuals and their families. Hence, stigma appeared to obstruct the delivery of vital social support to the family of the HIV/AIDS victim as well as to the victim him or her self while he or she was alive.

It appears that stigma goes further than one’s concern for one’s own safety within these communities, that is a fear of contracting the disease, but rather to a complete rejection of the infected person as being evil or bad for having contracted

the disease. Consequently, it appears that social opinion in regard to an HIV/AIDS related death is one of at the least indifference and at its worst anger or hatred towards the infected individual. The basic consensus being that the afflicted individual deserved to die because it was his or her fault for contracting the disease or because it was his or her inherent 'badness' that caused them to become infected. In any event, many of the caregivers reported that there was a lack of sympathy and compassion in regard to an HIV/AIDS related death.

Parents/caregivers of deceased cancer victims, on the other hand, portray a very different scenario. In many cases, the support of friends, family and the community far surpassed their expectations. Many parents/caregivers reported that they may have been better off with less assistance so that they could have spent more time with their deceased child before the death and could have moved on with their lives much sooner after the death. The mother of a teenage cancer victim voiced irritation at the suggestions, well-meant utterances of condolence and supportive interventions of family and friends after the death of her daughter.

Hence, while other bereaved individuals appear to receive a more than adequate supply of social support, the families of HIV/AIDS victims, are not only deprived from such social support but are in many instances reprimanded, condemned and criticized for the 'sins' of their HIV positive loved one for contracting the disease. Consequently, it appears that the bereaved families of HIV/AIDS victims are at a great disadvantage in terms of the resolution of grief due to the lack of social support.

Religious belief and the implications for HIV and non-HIV related deaths

According to parents/caregiver's reports, in relation to HIV/AIDS and non-HIV/AIDS related deaths, religious belief appeared to significantly impact on the resolution of grief. Parents/caregivers claiming to possess a strong belief in God or a higher power also claimed to be coping better with their bereavement. In addition, religious teachings attempt to satisfactorily answer questions of the unknown such as "where is heaven?"

However, in HIV/AIDS bereavement the issue appeared to be complicated with the negative connotations attached to HIV/AIDS infections and transmission. The sexually transmitted nature of HIV, its links to illicit sexual practices, the contracting of the virus by married men from extra marital relationships and passing on of the virus to innocent children add to social rejection of HIV/AIDS infected individuals and their families because of the obvious incompatibility between the above and socially accepted religious teachings and practices. Furthermore, while parents/caregivers felt a sense of allegiance to their deceased HIV positive loved one, they appeared to be uncomfortable with the notion that their child had committed a major sin and was being punished for his transgression with suffering and death, as was the case with a teenage HIV/AIDS victim or feelings of anger towards God for allowing such pain and suffering to be inflicted upon a helpless child, as was the case with the foster mother of a deceased HIV positive baby.

In regard to parents/caregivers of their adolescent or adult child who had become infected with HIV/AIDS through adulterous sexual encounters and unsafe

sexual practices, the religious transgressions of their children appeared to invoke a deep and prolonged sadness in the parents/caregivers. Aside from the obvious sadness arising from the death, there appeared to be an undercurrent of sadness that epitomized a deep feeling of disappointment in their child's behavior and the resultant consequences. This sadness was evident in the grandmother of young boy who died from HIV/AIDS. She says of her son who also died from HIV/AIDS and who infected his deceased son and wife, that there was nothing she could do because he was her son.

However, the belief in a merciful and loving God appeared to appease feelings of helplessness, sadness, regret and anger to some extent, allowing these bereaved parents/caregivers some comfort in their religious belief system.

Responsibility and culpability in HIV infection and transmission

Parents/caregivers report feelings of anger towards those they hold responsible for the infection or transmission of the disease to their young loved one. Hence, anger was likely to be directed at the afflicted individual if he or she was of the age whereby the surviving parents/caregivers to the infected individual, alive or deceased, could attribute such responsibility. The father of a teenage HIV/AIDS victim voiced irritation at his teenage son's lack of responsibility. He believes that it was this lack of responsibility that resulted in his son's infection with HIV and his subsequent death.

Parents/caregivers who had lost a child to HIV tended to re-evaluate their parental skills. This was clearly not the case with non-HIV deaths. Parents/caregivers

of children who had died from other causes such as cancer or an accident tended to feel as if they were justifiably neglectful of the other child or children because the deceased child's needs took precedence at the time but were now, after the death, able to make up for lost time with the surviving child or children. These parents/caregivers did not take the death as a discredit to their parenting skills. The HIV negative parents/caregivers of an HIV/AIDS victim, on the other hand, blamed himself for not disciplining or teaching his son good values and morals as his son had become infected with HIV/AIDS because of unsafe sexual practices. This father of a teenage HIV/AIDS victim claimed that he felt as if he had failed as a father because his son had been infected with HIV/AIDS.

Parents/caregivers of orphaned HIV/AIDS victims tend to support this view. The parents/caregivers seemed to view the deceased parent as culpable for the death of the child to HIV/AIDS. This culpability was also extended to the surviving family of the parents/caregivers such as grandparents. The foster mother of a teenage cancer victim claimed to feel angry with the deceased child's grandfather who she claims neglected him and in so doing caused the child to become sick.

In addition, there appeared to be confusion on the part of parent/caregivers in their assessment of HIV infection. They appeared to attribute HIV infection to a moral digression instead of a medical disease. The foster mother of a teenage HIV/AIDS victim described the deceased mother of her foster child, whom she claimed to have known only in passing from her church group, as being promiscuous and irresponsible. This same foster mother noted the responses of others in relation to her

foster sons HIV status in her community. She says, “He was a little child did not know about HIV- others did but behaved normally around him...everyone loved him, very loveable...only at school sometimes children would tease him”. She attributes the positive behaviour of family, friends and the community to her foster son as the result of her status and behaviour within the community. She claims to be well known, well liked and a contributing member of the community. She says that others did not react negatively to her foster sons HIV status because she and her family were positive towards him and comfortable in the management of his illness.

Cultural implications for loved ones afflicted by HIV and non-HIV related deaths

The findings of this study suggest that different cultures react differently to HIV/AIDS deaths. A Black mother of two mentions in relation to the death of a cousin, that even family members of the deceased appeared to shun her, “She (cousin) died the same day I came to see her. They didn’t do anything; they didn’t want to help her because she had AIDS. My mother, my aunt and everyone in the family cried but they didn’t want to do anything because she had AIDS. Before she died no one wanted even to give her medicine. I took the medicine and I said where is the gloves? She couldn’t even open her mouth. I cleaned her clothes and cleaned her nicely”. A coloured foster mother of a baby HIV/AIDS victim talks emotionally about the grief suffered by herself, her ex-husband and her adult biological children all of whom assisted in the care of the baby during her short life while another coloured foster mother mentions that “others did (knew about his HIV status) but behaved normally around him...everyone loved him, very loveable...” An Indian grandmother reported

that many people had warned her about taking precautions so as not to become infected her self but she believed that it was her son, daughter-in-law and grandchild, family and that family could not be discriminated against.

Chapter 5

Discussion

Introduction

Bereavement, mourning and grief are natural responses to the loss of a loved one. There are likely to be differences in the experience of grief across cultures as well as between the grieving response of children and adults.

The aim of this study is to explore the phenomenon of bereavement and examine whether bereavement due to AIDS is different from bereavement due to accidental death or other illnesses. Hence, this dissertation is an attempt to explore and expand on existing literature while possibly adding a new, more in-depth understanding of bereavement due to HIV/AIDS.

Reports by parents/caregivers in this study centered on the impact of the death on the preservation of one's sense of self or the preservation of existing relationships with surviving loved ones. A common problem was the adjustment of individual roles within the family now that the child or sibling had died. The importance of emotional and social support, the kind of relationship as well as the quality of the relationships established, and the freedom to mourn in one's own unique manner were expressed as significant to the grief process. Fluctuations in the experience of different emotions during the different stages of the mourning process as well as random movement back and forth from one stage of mourning to another highlights the significance of understanding individual experiences of grief. The gaining of a better understanding

of the grief response leads to better management of the bereaved in the community as well as better treatment and treatment outcomes for the bereaved patient.

In regard to the experiences of the family of HIV/AIDS victims' stigma was reported to hinder the grieving process by impeding the acquisition of social support. In this study social support emerged as a significant component in the successful resolution of grief. In addition, religious belief while therapeutic for non-HIV related deaths evoked, at the least, ambivalence on the part of the bereaved parent/caregiver in the case of HIV/AIDS related deaths.

Major findings regarding mourning.

Social and relational aspects of the grieving process.

Family relationships, attachment and the grieving process

Parents/caregivers that were experiencing greater difficulty with the bereavement appeared to be those whose need for the other was greatest. Weiss's (2001) view of the strength of the bond between the caregiver and child coupled with the understanding that a need satisfies a drive by appeasing a particular arousal state in an individual leads one to the conclusion that in order for the bereaved individual to successfully resolve their loss a replacement object is required.

The findings of this study suggest that bereaved parents/caregivers experience a need to fill the void left by the deceased child. Memories of the child remind the parent/caregiver of their loss resulting in painful feelings. In Freudian terms reference is made to hypercathexis (Freud, 1957) meaning that encountering an emotionally

painful memory or implicit assumption about a loved one who has passed on is often painful, intrusive, and preoccupying, and hence, detrimental to other mental processes. Freud (1957) contrasts this with decathexis which refers to the notion that being emotionally bound to someone means investing libido in one's mental representation of the person. When the person dies, the other must sort through mental representations of the deceased and decathect each mental representation to reclaim libido for subsequent relationships and commitments.

Many bereaved parents/caregivers in this study, and parents/caregivers cited by other researchers (Kalish, 1986; Knapp, 1980; Walter, 1999), claim that parents/caregivers report that they feel their deceased child's presence around them, in the child's bedroom, in the home or they see attributes of him in the faces of others. The parent's/caregiver's desire for a continuing bond with the deceased is clearly observable when interviewing bereaved individuals. While the idea of a continuing sense of the dead persons presence might seem to make the transition from life with the loved one to a life without him or her seem more bearable, it does carry significant risk. Bowlby (1980) claims that a continuing sense of the dead person's presence is a common feature of healthy mourning. Bowlby's theory posits that the survivor continues his or her bond with the deceased but in a different form rather than abandoning the deceased object to form new, material bonds with a new object, as is the case with Freud.

Confusion between a refusal to accept the loss and a healthy sense of the deceased child's presence could result in stagnation within the grieving process. As

opposed to a normal grief reaction, stagnation within the grieving process is likely to result in an abnormal grief response. Reports from parents/caregivers suggest that stagnation during this transition process results in an abnormal or pathological grief response. Bereaved parents/caregivers, who perceive themselves to be coping well, report the gradual release of their loved one to God or a higher power rather than the continued sense of their deceased child as being their ultimate goal. They appear to favour release of the loved one and the transference of feelings and needs now unfulfilled to be reinvested in another external object rather than resolving these unfulfilled needs and the resulting emotions within themselves. However, the ideal scenario appears to be a combination of Bowlby's (1980) and Freud's (1957) theories whereby the surviving caregiver retains a diminishing sense of the dead person's presence while simultaneously reclaiming libido for subsequent relationships and commitments.

A continuing sense of the deceased's presence becomes vital to the survival of the parent/caregiver, especially in the case of abnormal responses to grief. Roos (2002) addresses this issue with the concept of symbiotically enmeshed relationships where separation and individuation do not take place after infancy. According to her, when such a relationship exists, the parents/caregivers is unlikely to want to relinquish the relationship after the death "experiencing it not only as "killing" or rejecting the other but also as the killing or rejecting of self" (Roos, 2002, p. 163).

Consequently, a continuing sense of the deceased child's presence is unlikely to comfort or appease feelings of loss when faced with the physical absence of the

child unless parents/caregivers possess the emotional strength to continue grief work. In addition, an enmeshed relationship between parent/caregiver and child is likely to result in great emotional and psychological turmoil once the child has died. Kalish (1980) explains this phenomenon by saying that, “this may be true when a person has so over invested his emotional capital in another but he’s destroyed as a person in a loss of this other, when the loved experiences feelings of ambivalence towards a lost loved object that are so strong that the personality can not do the work of mourning without being involved in a large amount self-accusation or when a reaction to a loss cause a regression to an early emotional state in the demands of an externally supplied self esteem are not satisfied by the dependent relation to which the personality retreats” (p. 20).

It is not the initial response to the grief that points to an abnormal or pathological response experience but rather the duration and intensity of the response of the individual’s experience coupled with an adequate understanding of that particular individual’s personality configuration. In any event, as Kalish (1980) explains “when serious loss is sustained the measure of self-regard may become so weak that the being is not able to organize his resources for a more constructive work of mourning but rather takes upon itself the added task of self punishment, self justification or the building of magical explanations of the facts of life that could be more satisfactory dealt with by strengthening reality sense” (p. 39).

Attachment plays a crucial role in the experience of grief, affecting the bereavement process and the future resolution of the grief process. With a variation in

behavioural responses to grief and levels of attachment and attachment styles, family members progress through the bereavement process at their own pace. Different forms of coping may lead to misunderstandings in the grieving process between family members. These misunderstandings lead to the belief that one family member or the other was not very disturbed at the loss or was not working at resolving feelings of loss intensifying feelings of loneliness within the family unit.

In addition, bereavement experiences appeared to vary between individuals and between individual family members. Some individuals prefer to talk about the deceased, to reminisce about the deceased while others preferred to move on, and put the deceased and the past behind them. Differing manners of coping with the death resulted in miscommunication between bereaved individuals. Consequently, family members reported feelings of loneliness, confusion and vulnerability. Knapp's (1986), in his study on bereavement reported similar findings. In his study he described the experience of loss he observed in his participants as appearing as if, "A sense of vulnerability came to dominate family life for each family member left behind" (p.38).

Birth order and grieving

In this study, many of the deceased children were first-born children. Birth order plays a part in the loss of a child in two areas. Firstly, the birth order of the child predicts the role the child is likely to play within the family (Kaplan and Saddock, 1995), and secondly, the birth order predicts the attachment relationship between the child and each of the parents/caregivers (Ernst and Angst, 1983).

Exposure to multiple deaths

Reports by parents/caregivers who had lost more than one child, suggest that the bereavement response is directly linked to the kind of feelings and intensity of feeling attached to the deceased. For instance, a parent/caregiver who had lost two children may feel the absence of one of the children more than the other.

Consequently, the intensity of sadness and feelings of loss appeared to be less for the one child than the other.

The findings of this study suggest that the successful resolution of the grief process is more likely to be achieved if each of the bereavements experienced by the individual is worked through independently and completely. So while multiple deaths can give rise to what is termed bereavement overload (Kastenbaum, 1969, in Corles et al, 1994), it is not the case for all individuals that experience multiple deaths within their family or community. Rando (1993) cites eight types of dilemmas in mourning multiple deaths, each of which call for specific treatment interventions which are found in the following areas: 1) the approach to be taken in mourning multiple deaths, 2) prioritisation of the loved ones to be mourned, 3) differentiation among the loved ones, 4) loss of social support, 5) conflicts inherent in multiple deaths, 6) the overwhelming nature of the situation, 7) compromise of the six R process of mourning, and 8) survivor guilt (in Corles et al, 1994). Although each of these dilemmas may be important in organizing the overall grief process, each loss experienced appeared to run a separate and unique bereavement course. Rando's (1993) suggestion that steps be taken in order to deal with each bereavement

independently and completely, without carrying a residue of emotional baggage over into the next bereavement process can and does, as was the case in this study, facilitate a healthy grief response.

In addition, the findings of this study suggest that the experience of multiple deaths raises existential questions within the bereaved individual that hinder the resolution of the grief response. Reports by parents/caregivers suggest that questioning one's purpose on earth and being forgotten by parents or family point to existential issues playing a significant part in the resolution of grief. In addition, the opinion that the experience of multiple losses over a brief period of time tends to take longer to resolve (Harvey, 2002) is likely to be due to a separate process altogether rather than due to the build-up of multiple grief responses as Harvey suggests. So it appears that even though Harvey's (2002) research findings cited above suggest that the experience of multiple deaths can have a detrimental effect on one's sense of self, it also suggests that the effects of accumulative grief is likely to be due to existential issues such as questioning the reason for one's existence, the quality of one's life and one's personal perception of oneself being bad or deserving of such a fate. Harvey reiterates this point when he says that multiple deaths can have a greater impact on the individual than just a single bereavement experience in that individuals begin to question their fate, wondering whether they deserved it and whether their experience is typical (Lerner, 1980, in Harvey, 2002).

Loneliness and isolation

Parents/caregiver's reports emphasize likelihood of the grieving process resulting in isolation and feelings of loneliness. While "there is an intense drive to escape the pain, the devastation and the agony that the separation has caused them to experience" (Knapp, 1986, p.32), these parents/caregivers report a lack of understanding and emotional support on the part of the family and the community. A common belief carried by many of the caregivers was that one had to experience the loss of a child in order to understand their feelings. Hence reports of the house being so quiet or feelings of loneliness are comments that were frequently made by these parents, and unfortunately were comments that seldom elicited a satisfactory response from others.

In addition, the inconsolable nature of their grief makes it difficult for others to comfort them, resulting once again in feelings of isolation, helplessness and hopelessness. These feelings of isolation enhance feelings of helplessness and hopelessness, which in itself appeared to perpetuate the cycle, resulting in greater feelings of isolation. Knapp (1986) quotes a parents/caregiver as stating that "although we know...the acute state of mourning will subside. We also know we shall remain inconsolable and we'll never find a substitute no matter what may fill the gap even if it...filled it completely it nevertheless remains something else and actually this is how it should be. It is the only way of perpetuating that love which we do not want to relinquish" (p. 3). Parents/caregivers in this study voiced the same sentiment, claiming that it felt as if their feelings of loss and sadness would never end. Once again, a belief such as this made it difficult for them to find solace in others.

Grieving as coping alone.

Parents/caregivers reported being left to fend for themselves emotionally and socially when they felt they needed the support of friends and family the most. This study concurs with the findings of Knapp's (1986) study when he says that the lack of community support often intensifies the grief response. While parents/caregivers voiced their appreciation for support provided not only in emotional areas but also with practical issues such as funeral arrangements and apparently mundane day-to-day activities such as rearranging the child's room, which helped them cope with their loss, many of the respondents noted that offers of assistance, concern and care tended to diminish as the weeks passed on, resulting in feelings of abandonment and loneliness for the parents/caregivers who were still in the grip of their bereavement. Walter (1999) elaborates on this process by suggesting that a lack of community support may result in a fear of social isolation that appears to respond to societal pressure to "get over it" or "move on with their lives" by suppressing grief responses which can result in their grief reaction manifesting in a shadow form. Interestingly, this phenomenon can precede the death. Knapp (1986) notes that the tendency of others to withdraw is also noted during the months of care for a terminally ill child.

Parents/caregivers report common problems when faced with the death of the child. Some of the problems mentioned appear quite mundane, may be taken for granted and could easily be overlooked by well wishing friends and family, such as how to manage the first grave visit, while others, such as problems with the autopsy for instance, may have not occurred to individuals who have not been faced with such

a situation. Knapp (1986) lists some common problems experienced by parents and families who have lost a loved one, all of which have been at some point voiced by the parents/caregivers who participated in this study.

These include a) The lack community support in trying to adjust to the aftermath of child death, b) Some of the unique problems encountered during the hospitalisation of a child for a terminal illness and also the assessment of the important needs of children during these times, c) The physician and his or her reaction parents/caregivers suffering the tragedy of the death of a child. Many Doctors are untrained in dealing with the emotional upheaval such as (experiencing death), d) The autopsy in the problems encountered with this procedure, e) Some ways of anticipating, planning for and handling funeral arrangements and the funeral experience itself, f) Grave visits and the variable impact that this has in the family, g) The child's room or a special place in a home and what this means to the parents survivors, and h) Special days and the stress these times produce for the family (Knapp, 1986, p.23).

All the problems mentioned above require the involvement of the key role players, which inevitably is the parents/caregivers. Bereaved parents/caregivers at or near the time of the death are not in the frame of mind to manage such demands in a rational and logical manner. Consequently, it is at a time like this that community support that addresses these issues are much needed.

Unfortunately this kind of support was seldom available to the parents/caregivers of the deceased HIV positive children who were often met with insensitive words and inappropriate responses at these critical times. In addition, friends and family on occasion criticized their management of some of the issues mentioned above. Some parents needed quiet times to reflect but were seldom left alone; others longed for companionship but were often avoided. It seems as if “so few, and this included close relatives and friends, really knew how to respond to the death of a child and how to truly meet the needs of the survivors” (Knapp, 1986, p. 136). Consequently, an understanding of the special needs of bereaved parents/caregivers is an important component of the successful resolution of grief, before and after the death of the child.

Conversing about the dead.

Conversing about the deceased appeared to be an important component in the resolution of grief among parents/caregivers in this study. Those individuals who were able to converse adequately about their child appeared to cope better than those that did not have the opportunity to or were unable to do so.

The failure to converse about their child whether for personal reasons or as a result of external factors tended to precipitate feelings of isolation. As these feelings could not be expressed openly, they express themselves in other ways. Hence, the findings of this study suggest that feelings of guilt and pain tended to be internalised and give rise to physical symptoms such as chronic headaches, insomnia, stomach, digesting problems, and so forth, spiritual distress and neurotic and antisocial

behaviours. Knapp (1986) research on bereavement supports these findings. Hence, according to Knapp (1986) “letting go or facing painful memories may be related in a very meaningful way to the kind of adjustment one is able to make in regard to the empty room” (p.176).

The surviving children of some of the parents/caregivers were said to keep and play video material where the lost person was featured, breathing new life into precious memories, too valuable to be relinquished. It is imperative that bereaved individuals eventually say goodbye to their beloved, accepting the fact that they will not return, and nothing will ever replace their lost loved one. While revisiting happy times spent with the deceased can be a valuable means of relinquishing the deceased by reprocessing and assimilating a new cognitive representation of the deceased (Bowlby, 1980), it could also be a means of holding on to the deceased. According to Shaver et al (in Stroebe et al, 2001, p. 81) and as mentioned earlier in this study, there is a hidden danger in what is referred to as the “continuing bonds” theory. The latter denotes an individual who constructs continuing mental relationships with deceased figures, in such a way that one is always bound by the grief, always looking for the lost loved one and trying to replace the loved one by moulding others to be like him or her.

Fluctuations in grieving

Stages of bereavement

The findings of this study suggest that there are elements of similarity and differences between the different theories of bereavement regarding the stages of

bereavement, stages of dying or tasks of mourning, for instance, are all addressing the same process, with similar, if not the same, key markers but from differing angles. Hence, components of these above-mentioned theories are present in all grief responses. For instance, there is consensus between the different theories over the existence of stages within the grieving process. However, there appears to be a difference in the point of reference (addressing the needs of the loved one or the plight of the dying), labelling (the name given to a particular stage), the depth and the magnitude of the description between the different theories.

Although the findings of this study suggest that the stages of dying cited by Kubler-Ross (in Bracken, 1986) and stages of grief cited by Dane and Miller (1992) have similarities differences do exist between the different theories. For instance, in the different theories certain stages may be intensified, minimized, modified or left out altogether.

According to Dane and Miller's (1992) theory the stages of grief do "not have a fixed sequence and not everyone goes through all the stages" (p. 10). Hence, the findings of this study suggest that the length of time it takes for an individual to pass through each of the stages is not fixed, neither is it possible to predict the sequence or intensity that each individual is likely to experience during these phases or stages. Each individual experiences his or her individual grieving response in his or her own unique way. Parents/caregivers reported diverse and random grief responses.

However, even though the findings suggest that it is highly unlikely, if not impossible, for two individuals to experience the grieving process in exactly the same manner, the research appeared to indicate that the tasks and stages are indicative of a common thread that, to different degrees, weaves through all bereaved individuals regardless of the communities and cultures that they belong to.

Normal and abnormal grief

The findings of this study suggest that it is important to the management of the grief response to be able to distinguish between normal and abnormal grief. Walter's (1999) study on grief supports this view, also suggesting the importance of distinguishing between a normal and an abnormal grief response. Parents/caregivers in this study reported symptoms similar to those reported by Knapp (1986) such as the symptom of disorganization, which appeared quite prominently among parents/caregivers in this study, hyperactivity, agitation, jitteriness and talkativeness. In this study, many parents/caregivers reported the symptom of disorganization. Knapp (1986) goes on to state that symptoms such as agitation and jitteriness were disconcerting to family and friends. In addition, bereaved individuals display an inability to retain information that often manifested in repeated requests that things be done or that people be notified even after being told repeatedly that the requests have been taken care of. "His or her ears were not connected for hearing nor the eyes were seeing, a sign of intense confusion of this period" (Knapp, 1986, p. 137). Hence, normal reactions to grief are accompanied by severe psychological discomfort, for the bereaved and as a result of this, for friends and family.

As a result of the discomfort evoked by these feelings by the bereaved in family and community members a state of apathy may be preferred in a bereaved individual by friends and family in order to alleviate their own uncomfortable feelings of, for instance, helplessness when faced with the more difficult to manage feelings evoked by bereavement such as crying or inconsolable sadness in the parent/caregiver.

It is interesting to note that not all bereaved individuals experienced these psychosomatic symptoms, once again highlighting the importance of taking individual personality characteristics into consideration in the classification of bereavement reactions as normal or pathological are complicated by a diverse set of physical, psychological and emotional responses and should be acknowledged as such. For instance, such symptoms immediately or soon after the loss of a loved one could be classified as falling within the normal range of reaction. However, experiencing such symptoms two years later to the mention of the deceased is likely to be cause for concern.

Hope and focus on the future.

The findings of this study suggest that the expression of hope and a focus on the future play a significant role in the resolution of grief among parents/caregivers of dying children. In particular, this study suggests that hope affects the outcome of the grieving response. While the researcher acknowledges that hope may be the result of improved coping. In this study, those parents/caregivers who reported to be hopeful and planning for the future also reported coping better with their loss. Hence the

expression of hope appears to play a key role not only in the psychological well being of the individual but also in the preservation of life. For instance, without hope that it will get better one would not have the will to work through the grief in order to survive from day-to-day after the loss of one's child. The roles that hope plays in the management of their child's illness are also evident before the death of the child. The status and development of hope was evident in the report of parents/caregivers.

In regard to parents/caregivers of children who have died from an illness, after the initial shock of the diagnosis, parents/caregivers thought of their child's condition in very positive terms. "They operate under the assumption that all will be well, it is at this time that they rearranged their priorities and change their focus as to concentrate on the present situation that discard all future plans and future commitments. They live on the day-to-day basis relying on whatever treatment protocol is recommended and maintain a tenacious hope for their child's ultimate survival" (Knapp, 1986, p. 55). While hope may be a result of better coping rather than the other way around, in this study, hope appears to allow the bereaved parents/caregivers the opportunity to hold onto the belief that the child will survive and also motivates them to begin and continue with treatment programs. In this manner, the parents/caregiver is able to "buy time", so to speak, in order to process the possible loss of the loved one. At this instance in time, it is important for one to note that to the parents/caregivers it is still a possible rather than an inevitable loss.

Knapp (1986) explains this phenomenon very well in this description, "optimism, coupled with a sense of determined hope is passed onto the child, leading

to a determination to survive that is difficult to penetrate even during very last moments when death is pending” (p. 56). As one can see, feelings of hope not only make it easier for the parents/caregivers and child to cope but they also enhance the child’s chances of survival by enhancing the acquisition and implementation of treatment regimes by his or her parents/caregivers.

In this way, reports by parents/caregivers suggest that the expression of hope also plays a part, although differently, in the days before death. According to Knapp (1986), the final moments is not attached exclusively to survival but also to the way life is brought to an end. Hence, he says that the way the final moments of life are handled by parents/caregivers and the assurance they have that they can have some control over the final event is also a part of the complex of hope that the parents/caregivers display. In light of this, the character of their hope changes from hoping for survival to hoping for full range of living in the time they have available and the comfortable pain free death of their child (Knapp, 1986).

In addition, the findings of this study suggest that hope and a focus on the future make their appearance at different times and in different contexts before and after the death of the child with hope, at times, appearing independent of future focus or planning. For instance, after the death, hope and a focus on the future become obvious once again during the stages of relief and re-establishment, which represents a final stage of grieving process after the death. In this stage, the bereaved individual becomes involved in the process of re-establishing himself or herself in the world around him or her (Knapp, 1986). Knapp’s (1986) list of pointers for bereaved

parents/caregivers reiterates the importance of hope and future planning in the bereavement process. He claims that it is important to recognize the loss and accept the feelings of grief that result from such a loss.

Consequently, feelings of hope and a focus on the future change over the bereavement process. The process of accepting the eminent death of the child begins with hope and a focus on the child that he or she will be cured. This process then transforms into hope that the parents/caregiver is able to do his or her best for the child now and in the near future. And, finally to the hope and a focus on the future that life will get better for the parents/caregivers after the resolution of grief. Hence, while hope appears to be constantly present, with its form and context constantly changing, a focus on the future only appears to present itself during certain stages in the grieving process. A focus on the future then can be utilized as a reliable marker in the assessment of individual bereavement processes in that the positive resolution of a particular phase or a particular process such as denial or guilt can result in the acknowledgement that one will have a future and by implication then, that one will survive the loss of one's child.

Anticipatory grief.

The findings of this study suggest that anticipatory grief did not have a positive influence on the grieving process of bereaved parents/caregivers. Parents/caregivers claimed not to be prepared for the death in the least, even when they were explicitly informed by health care professionals of the imminent demise of their child. Even parents/caregivers who had attended family counselling sessions

before the death with the then terminally ill child appeared to deny the possibility of their child dying. While these parents/caregivers found that the counselling sessions helped them better understand their son or daughter and helped her resolve past grievances with her parents, it did little to minimize the shock of her death or help them resolve the resulting grief. If anything, parents/caregivers reported that the counselling sessions brought up issues with their child that they up until then were unaware of. In other words, these parents/caregivers were of the opinion that counselling complicated their parent- child relationship further, adding more stress at a difficult time in their lives.

Futterman and Hoffman (1970) describe a series of 5 stages which they believe collectively described anticipatory grief, they are, “a) acknowledging that the child’s illness is terminal, b) grieving in response to this knowledge, c) becoming reconciled to the child’s death by finding meaning in it and in the child’s life, d) becoming somewhat emotionally detached from the child and e) memorizing the child by forming a lasting mental image of him or her” (in Aiken, 1977, p.175). Most parents/caregivers experienced great difficulty accepting their child’s death after the death. Two out of the eleven parents/caregivers interviewed appeared to be working with the task mentioned in three above, that is, becoming reconciled to the child’s death by finding meaning in it and in the child’s life. The other nine parents/caregivers did not volunteer any information during the interview that implied that they had found meaning in their loved ones demise. Rather there appeared to be a conscious decision to “put behind” them what had happened and “move on” with their

lives and the responsibilities the deceased, in many instances, that had now fell upon them to fulfil, such as the care of the surviving family members.

Regrets and guilt

Regret is an “unpleasant preoccupation with something in the past, something we had wished had never happened or not happened in that particular way” (Kastenbaum, 2000, p.88). Hence regret is closely related to grief and guilt. The main concern voiced by parents/caregivers was for the comfort and well being of their child. For instance, in regard to the hospital experience, the majority of the parents/caregivers complain that the hospitalisation of their child was as confusing and traumatic for them as for the child and many often did not know how to respond to the unique demands facing them at these critical times. In addition, parents/caregivers complained of a lack of privacy and time alone with their child. Knapp (1986) cites a similar response in his study of bereaved parents; he states that parents have a strong desire to experience these precious moments alone with their child in a quiet and privacy of their home. While the parents/caregivers in this study claimed to have done their best to make the child comfortable and address all of his or her needs, as Kastenbaum (2000) above cites, guilt appears to play a significant role in the presence of regret. All the parents/caregivers constantly reiterated their efforts to have done their best for their child during his or her illness. Hearing their own declaration of commitment and love for their children and the service that they provided appeared to have a calming effect on them. Hence, in hearing these declarations of service and dedication to their loved one the parents/caregivers were able to appease their feelings of guilt at the loss of their child. Walter (1999) agrees

with the findings of this study when he posits that cultural norms tend to propagate certain assumptions. For instance that parents/caregivers be the protectors of their children, that having children be a means of social status and that it is natural for the old to die and not the young all lend credence to parents/caregivers perceptions of having somehow failed their children which then results in guilt feelings.

Consequently, society is likely to perpetuate this belief system.

Children approaching their own death need emotional support and nurturance in relation to the emotional aspects of the death as well as physical care required in relation to their illness. This study supports Knapp's (1986) findings when he says that the over emphasis on the death of the child and the frantic effort to avoid it even to the very end is unfortunate as parents/caregivers often missed vital opportunities to satisfy the important emotional needs of their children and missed the chance to experience the sharing of deep, intimate and emotional exchanges with their children as the child approached death. This scenario then results in feelings of guilt and regret on the part of the parent/caregiver once the child has died.

Family reorganization and adjustment to loss

Parents/caregivers expect surviving children to take over the role of the deceased. When the surviving sibling resisted such expectation, parental/caregiver reaction appeared to be severely critical. In addition, parental/caregiver expectation appeared to be transferred to close friends and family. Hence, the sibling then became inundated with stimuli that reinforced parental/caregiver expectations for the sibling to fill the void left by the deceased. For instance, friends and neighbours

“accidentally” calling the surviving sibling by the name of the deceased reinforced this comparison between the deceased and the surviving same-sex sibling.

Furthermore, evidence of idolizing the deceased was evident in reports by parents/caregivers in regard to problems experienced with surviving children. Parents/caregivers tended to openly compare the surviving child to the deceased. This was especially evident in relation to same-sex siblings. Parents/caregivers report that the deceased was the kindest, most generous, good-natured, warm hearted and loving person they had ever known. They cite the responses of others as proof of this belief. For instance, they quote conversations, words of condolence and offers of sympathy that the doctors, nurses and other professionals or hospital staff agrees with their opinion. While idolizing the deceased may be a normal part of the grieving process, the consequences for the bereaved sibling when parental/caregiver expectation such as the above leads to critical condemnation and insult results in a complicated grief response. Reports by parents/caregivers support this notion in that most report that their child did not appear to have resolved their grief response. In addition, parents/caregivers, especially those in which a significant amount of time had passed since the death voiced concern for their surviving child.

Kalish (1980) claims, “one of the reasons that the bereaved idealize the deceased is that it probably is the simplest and best form of resolving the guilt feelings that exist” (p. 89). The flip side of this is that the parents/caregivers, not wanting to relinquish the memories of their deceased child, may try to replace the lost loved one by moulding others (in this study, the surviving sibling/s) to be like the

deceased child. For instance, the room of the deceased child appeared to play a role in revealing such an agenda, from the parent insisting on the room remaining exactly as it was when the child was alive, and forcing the remaining sibling to live in it, as it was to clearing out all the belongings of the deceased as soon as possible. Knapp (1986) explains this scenario when he says “it (the room) might be left just as it was at the time of death with nothing changed. In these cases the parent or parents may wish to surround themselves with as many memories as possible. This might be their way of clinging to remnants of the child that they find comforting thus this could be the way of denying death or at least avoiding reality” (p.176).

Anger.

Reports from parents/caregivers reveal feelings of anger during the initial stages of grief, during the stage of violent emotions, and as denial begins to fade. Feelings of anger, resentment, hostility, vindictiveness and distrust cause the survivor to lash out at those around him. As a result of this anger, communication problems inevitably arise between family members. Reports by parents/caregivers suggest that the bulk of these angry feelings tend to be off-loaded on the surviving children. Anger tended to manifest in over-protection of the surviving children with no feasible explanation for action being offered to the child, a lack of consideration in regard to the surviving child's needs and feelings and an overly critical and judgmental attitude towards the surviving child.

According to Knapp (1986), this kind of anger is obvious because these bereaved individuals tend to lash out at everyone and anyone, “this might have been a

husband or wife, son or daughter, brother or sister, doctor, the paramedics and the ambulance attendants, nurses, emergency room personnel, neighbors, friends and any one with reach” (p.138). However, in this study much subtler forms of anger appear all through the grieving process.

In this study, reports by parents/caregivers suggest the experience of anger during the transition from one stage of the bereavement process to the next. Bereaved caregivers mention feeling indiscriminate anger towards other people at different stages of the grieving process. While it is obvious that the presence of angry feelings points to the presence of unresolved issues, whether these are old feelings of anger rising from unresolved past issues or whether the angry feelings are a result of new issues that have come to light due to the resolution of the different phases of grief needs to be seen. Whatever the case may be, some level of anger, in whatever form, appears to weave through all stages of grief process. Consequently, in order to reduce feelings of anger once initiated, anger needs to be constructively and appropriately channeled (Roos, 2002). Hence, once again, significant reduction of anger is likely to result in better outcome for the bereaved.

Denial.

The parents/caregivers of the deceased children interviewed in this study appeared to struggle predominantly, if not solely with the terminal nature of the illness from the time of diagnosis until the death of the child. Freitman et al (1963) note that parents who strongly maintain denial throughout the illness must experience the grief at once at the time of death, for them that often brings an intense grief

reaction in weeks, months or several years that follow (in Chodoff, Mason and Hamburg, 1960).

The findings of this study suggest that where denial, described by Knapp (1986) as a psychological defence equipping mechanism that comes into play after the shock subsides, is operating, no emotional recognition of the loss and therefore no expression of genuine grief is possible. In some cases denial was very long, extending for months into the post-death period. One form of denial in which the person overtly denies the terminal nature of the illness, is obvious. In this study, such reaction as described above was evident after the death of the child rather than before. It appeared that much of the above had not been addressed before the death. The lack of preparation for the death of the child resulted in the bereaved caregiver experiencing more confusion and stress. As a result many of the bereaved relied and it appeared became dependent upon the kindness and resources of family and friends.

Parents/caregivers voiced regret at not having spent enough time with their child, having the child die away from home or being grateful that the child died at home. It appeared that these parents/caregivers were so involved in the care of the child and the fight to “beat” the illness that planning for the future did not appear to feature in their day-to-day lives.

The comparison of grieving over deaths from HIV/AIDS and non-HIV/AIDS deaths in the South African context

The comparison between bereavement due to deaths from HIV/AIDS and bereavement due to death from other causes yielded interesting results in that while the manifestation of the grieving response remained constant, individual perception and management of the grieving process seemed to differ between the loved ones of HIV positive and non-HIV positive deceased children.

HIV related stigma and grief.

Parents/caregivers of HIV/AIDS victims reported the experience of stigma towards HIV/AIDS victims within their communities. In addition, they cited experiencing stigma as being a determining factor in the availability of social support within their respective communities. Consequently, the findings of this study suggest that stigma plays an important but debilitating role in the grieving process of the bereaved parents/caregivers of an HIV positive individual.

As parents/caregivers report, community members and family become scared or afraid to work with the dying HIV positive child, or his or her family once he or she has passed on. Interestingly, the parents/caregivers of HIV/AIDS sufferers interviewed in this study were willing to talk about their child's HIV positive status with family, friends and the community. Many of the parents/caregivers reported feeling hurt or angry about the negative effect of stigma on the short life of their deceased child. Interestingly, parents/caregivers of non-HIV related victims claimed

to be overwhelmed with the support they received from the family and the community.

Guilt at causing death

The findings of this study suggest that parents/caregivers who infected their children through vertical transmission of the HIV virus felt guilty about their child's HIV status. In addition, these guilt feelings appeared to hinder the resolution of grief.

Reports by parents/caregivers who were not physically responsible for infecting their child suggest that they also felt responsible for their child's infection. These parents/caregivers claim to feel guilty at not having taught their child good morals and values and at not having taught their child safe sex practices. They believed that they had failed as parents/caregivers because their child had died from HIV/AIDS. Hence, these children such as the above are not likely to have the opportunity for closure prior to their death due to the ambivalent and complicated mourning experienced by their loved ones. In addition, the lack of closure experienced by the deceased prior to his or her death is likely to be transferred to the surviving loved ones once he or she passes on, hindering the resolution of the grief.

Religious belief and the grieving process in HIV and non-HIV deaths.

In AIDS related and non-AIDS related deaths the conflict over religious belief in an all loving and nurturing higher power was threatened by the death of their child that questioned "God's loving nature" (Knapp, 1986). Knapp (1986) and Grollman (1995) support this study's finding that many parents/caregivers report losing faith

during these critical times and turned away from God and religion because they held him responsible for the death of their child. “The denial of God is usually subjective and related to strong feelings of rejection in the life of the individual, who feels impelled to project these feelings out into the universe” (Jackson, 1985, p.218).

Closure is an important aspect of grief resolution and a belief in God allows the parents/caregivers to release the child “to a better place”. The findings of this study suggest that in HIV related deaths the denial of God obstructs or hinders the process of gaining closure after the death. This does not appear to be the case in non-HIV related deaths where community support as well as strong religious convictions was reported by caregivers and parents to play a significant role in the management and resolution of grief.

Different religions may find different explanations but all religions systems address issues of life after death, heaven, the innocence of children, the beauty and peace of paradise and the eventual reuniting of the living with the deceased loved one. However, religious belief proves problematic from the stand point of HIV/AIDS. In many instances, HIV/AIDS has become synonymous with “unnatural” and sinful practices such as homosexuality, adultery and prostitution.

Parents/caregivers in this study turned to their religious faith as a means of coping with the death of their child. Knapp (1986) supports these findings in his study on bereavement. Reports by parents/caregivers cite a belief in God as helping resolve grief while turning away from the belief in God, also a means of coping with the

death, appeared to hinder the grieving process, and appeared to lead to feelings of confusion, fear, excessive anger and ambivalence in the surviving parent or parents. While many of the parents/caregivers of non-HIV victims took solace in their religious belief system, the families of HIV/AIDS victims, appeared to experience difficulty in accepting God because of the “sinful” status of being HIV positive if the child was responsible for infection, and the mercilessness of God for having made an innocent child suffer for the sins of his or her parent if the child was infected by his or her parent.

In any event, all parents/caregivers reported increased interest in religion that they report to be as a result of their child’s illness and subsequent death. Knapp (1986) and Grollman (1995) also cite a revival, a renewal or intensification of their religious faith in their study of bereavement. Positive changes in the pattern of parents/caregivers religious responses were important because they led to the establishment of effective personal remedies for dealing quite effectively with the loss and helped parents find some answers and comprehend the event they were experiencing eventually resulting the partial resolution of the acute phase of grief (Knapp, 1986).

The main concern expressed by the parents/caregivers interviewed was the general well being of their deceased child. This finding is supported by Knapp (1986) when he says that “A significant number of parents tended to reject the idea of total annihilation of their children...In this way, death in the sense of final separation was avoided...Considering that the child is living or existing somewhere else place a

lighter burden on the parent making the whole affair somewhat easier to fit them” (p. 82). According to Grollman (1995) religion and faith eventually in the minds of the majority of parents/caregivers, becomes the only logical and satisfactory explanation of what happened. “Many parents have in fact blamed God and held him responsible indicating that...at the time it was good to be able to hold someone responsible” (Grollman, 1995, p. 204). Hence, religious interpretation of the death allows the parents/caregivers the opportunity to reduce feelings of guilt and self-blame resulting in the resolution of some of their grief response by finding in religious belief an appropriate explanation of how and why their child died (Walter, 1999; Head, in Corles et al, 1994). Reports from parents/caregivers of HIV/AIDS victims in this study do not support Knapp (1986) or Grollman’s (1995) notion as it appears that the parents/caregivers in this study believed themselves to be at least partly responsible for the death of their child implying that they could have done something at sometime in the past to prevent death from HIV/AIDS.

The findings of this study suggest, and are supported by Walter’s (1999) findings, that parents/caregivers appeared to have a need to find some meaning in the loss of their loved one. For instance, parents/caregivers with strong religious beliefs tried to come to terms with the death in religious terms, such as the child was now in a better place or we will see each other once again. Spiritual parents/caregivers may reason that everything happens for the best. Knapp (1986) in his research on bereaved families reiterates this point claiming, “It was rare family indeed who could have simply accepted the death of a child as an act fate. They had to develop a sense of control over the event; parents needed a way of justifying the death in their own

minds” (p. 34). In time these parents/caregivers began their search for logical reasons for the death. In essence they searched for assurance that the loss was not in vain. Eventually, “the most common place where the child was conceived to existing was defined in religious terms, the place was heaven or an afterlife” (Knapp, 1986, p.84) and a comforting accompanying belief was that the deceased child was in the company of other deceased family members. A subtle inclusion in this belief system is the notion that at some point in the future the grieving parents/caregiver will be able to reunite with his or her deceased child (Knapp, 1986). However, parents/caregivers of HIV/AIDS victims in this study did not appear to find solace in the notion that the HIV/AIDS victim was now in a better place, as was the case with the non-HIV parents/caregivers.

Interestingly, most of the parents/caregivers of HIV/AIDS victims did not mention the perceived whereabouts of the deceased as was the case with the non-HIV victims whose parents/caregivers constantly mentioned that their child was with God or in a better place or safe and happy with loved ones or in heaven. In addition, while almost all parents/caregivers admit to praying for the deceased, non of the HIV/AIDS parents or caregivers mentioned reuniting with the loved one in the future. The underlying belief or perception that parents/caregivers, especially of those children responsible for their own HIV infection, are likely to be suppressing or at the very least denying is the feeling of belief that their loved one is lost for ever, never ever to be seen, heard from or experienced again. These parents/caregivers fear that their child is not in a safe place, happy and comfortable. However, even in babies and young children, parents/caregivers appeared to avoid talking in terms of death, dying,

the mercy and love of God. The common perception was that what kind of merciful God would let a child suffer so much pain. Hence, as the findings of this study suggest the perception then that a loss due to HIV having far greater repercussions for the parents, caregivers and loved ones of the deceased than a death due to another cause becomes more plausible.

Conceptual conclusion and implications of the results

It is not possible to understand the difference between bereavement due to HIV/AIDS deaths and bereavement due to other causes of death without understanding the normal expression of grief among parents/caregivers of deceased children.

Researchers such as Dane et al. (1992), Kavanaugh (1974), Kubler-Ross (1969) and Worden (1982, 1991) describe different stages of dying. While there is controversy over the stages of dying described by the above-mentioned researchers, their respective theories describing the different stages of dying are widely accepted as legitimate theories of bereavement (Fogarty, 2000; Grollman, 1995). However, the findings from this study suggest that these theories, while adequate theories of general bereavement, are not adequate in explaining or describing bereavement due to HIV/AIDS.

Bereavement due to HIV/AIDS is different from other forms of bereavement. Hence, a theory that attempts to describe or explain bereavement due to HIV/AIDS requires an adaptation of general theories of grieving. The findings of this study

suggest that key factors in HIV/AIDS bereavement such as lack of social support, stigma, guilt arising from religious belief, and guilt regarding responsibility or culpability for infection with HIV, affect the successful resolution of grief in bereavement due to HIV/AIDS.

In this study, one of the key factors that affected bereavement in HIV/AIDS related deaths was stigma. Stigma appears to impact negatively on the grieving process in HIV/AIDS related deaths. It promotes silence between individuals, which perpetuates the problem by encouraging misinformation and misunderstanding regarding HIV/AIDS. In addition, stigma appears to have a domino effect on the bereavement process in HIV related bereavements in that stigma affects the level of social support available to the bereaved loved ones of the deceased HIV positive individual. Reports from parents/caregivers suggest that social prescriptions, individual perceptions and beliefs, and ignorance in regard to HIV/AIDS play a pivotal role in the perpetuation of stigma against HIV/AIDS infected individuals and their families.

In any event, once differences in bereavement are identified by studies such as this, the utilization of such knowledge can result in the development of special interventions. In addition, new management and treatment programs tailor made for the South African context can be developed resulting in better service provision and improved treatment outcomes within the community. Due to the magnitude and scope of HIV infection and death in South Africa, such bereavement programs are likely to have far reaching positive effects on the psychological health and well being of

bereaved parents, children, extended family and caregivers of HIV infected adults and children. It therefore follows that while bereavement is a natural response to loss, a careful monitoring of the bereavement process in HIV related bereavement will allow one to tailor the management of the bereavement or treatment to the deceased HIV positive individual's bereaved loved ones particular needs.

Consequently, one of the implications of this study is that a better understanding of bereavement due to HIV/AIDS will result in improved understanding; better management and more successful treatment of bereavement in the families of deceased HIV infected individuals.

Limitations of the study.

Population may be described as the entire individuals or elements that meet a study's sampling criteria (Burns and Grove, 1997). In this study the parents/caregivers who elected to participate in the interviews were the family of deceased patients of the Highway Hospice in Westville, Durban. As the only participants included in the study were those from the Highway Hospice it is difficult to generalize the findings of the study. Although debatable, in order to develop a more valid response to any particular area of the research, more homogeneity within the group may prove to be more beneficial. Consequently, future research should include a larger and more diverse sample.

The researcher preferred to see the respondent in their own homes as this gave a better picture of their social and environmental reality and the manner in which they

were coping with the death of their child but the venue was decided upon by the caregiver or parent. If the parents/caregivers was able to accommodate the interview at their home then the interview was carried out at their home. However, some parents/caregivers preferred to be interviewed at another venue such as their place of work. A single, prescribed venue, such as their home, would have been preferable as the researcher found interviews carried out in the subjects home to be valuable in assessing the subjects present level of functioning and hinted at the current stage of mourning. For example, signs and symbols of the deceased plastered on walls and side tables to the exclusion of memorabilia of the existing children or the deceased still possessing a room in the home regardless of space shortages was distressing at the very least but provided valuable insight into the psychological state of the bereaved parents/caregivers and possible problems that may arise between the parent/caregiver and other family members. In addition, parents/caregivers appeared to feel more comfortable within their own homes and volunteered more information about their home environment when in familiar surroundings.

Conclusion.

The findings in this study point to there being a difference in bereavement experienced by family members of those whose children had died from an HIV/AIDS related illness and those who had died due to other causes. This difference appears to be directly related to the stigma attached to HIV/AIDS and not to psychological, social, economic or environmental factors surrounding the deceased or his or her family. Factors such as helping other cope with bereavement, strong religious belief, good relations between immediate family members and the presence of a healthy

attachment to the deceased seem to be key factors that help facilitate the successful resolution of the grief response. However, grief over the loss of a child is never completely reconciled but rather transformed into a milder, less active form of grief often referred to as shadow grief. Regrets and comments by the parents/caregivers on their bereavement process centre on social and family concerns and hint at a lack of guidance, knowledge and structured management programs in the area of bereavement in relation to the above. A program designed to address the individual needs of South African's in the management of bereavement is highly recommended.

References.

- Aiken, L. R. (1982). Psychological testing and assessment (4th ed).
Massachusetts: Allyn and Bacon.
- Aiken, L. R. (1985). Dying, death and bereavement. Massachusetts: Allyn
and Bacon Inc.
- Aiken, L. S. and West, S. G. (1990). Invalidity of true experiments: Self report
pre-test bias. Evaluation Review, 14, 374-390.
- Ainsworth, M. D. S., Blehar, M. C., Waters, E. and Wall, S. (1978). Patterns
of attachment: A psychological study of the strange situation. New Jersey: Erlbaum.
- Alexandra, I. E and Adlerstein, A. M. (1958). Effective responses to the
concept of death in a population of children and early adolescents. Journal of Genetic
Psychology, 93, 167-177.
- American Psychiatric Association. (1996). Desk reference for the diagnostic
criteria from DSM-IV. Washington: American Psychiatric Association.
- Anderson, J. (Ed.). (2000). A guide to the clinical care of women with HIV.
Human Resource and service administration: U.S. department of Health and Human
Services.
- Bartlett, J. G. and Finkbeiner, A. K. (2001). The right to living with HIV
infection developed at the Johns Hopkins Aids clinic (5th ed). Baltimore: The Johns
Hopkins University press.
- Becvar, D. S. (2001). In the presence of grief – Helping family members
resolve death, dying and bereavement issues. New York: Guilford Press.
- Benoliel, Q. (1994). Advanced nursing science: Qualitative approaches.
Western Journal of Nursing research, 6, 1-8.

Bertoia, J. (1993). Drawings from a dying child – insights into death from a Jungian perspective. London: Routledge.

Bluebond-Langner, M. (1978). The private worlds of dying children. NJ: Princeton University Press.

Borgatti, S. (2005). Introduction to grounded theory. Retrieved 14 January 2005 from the World Wide Web: Indoglobal.com web services.

Bowlby, J. (1969). Attachment and loss. Vol. 1. Attachment. London: Basic Books.

Bracken, J. M. (1986). Children with cancer: a comprehensive reference guide for parents. New York: Oxford University Press.

Brown, E. (1993). The experiences of twelve families with a child profound and multiple learning difficulties. Unpublished research, Oxford University, United Kingdom.

Brown, E. (1994). Children death and grief. Unpublished Masters dissertation, Oxford University, United Kingdom.

Brown, E. (1999). Loss, change and grief an educational perspective. London: David (Flawton) Publishers.

Burns, N. and Grove, S. K. (1997). The practice of nursing research conduct, critique and utilisation (3rd ed.). Philadelphia: W. B. Saunders.

Chodoff, P., Mason, J. W. and Hamburg, D. A. (1960). Behavioural observations on parents anticipating the death of a child. Paediatrics, 32,610-625.

Cook, A. S. and Oltjenbruns, K. A. (1989). Dying and grieving – lifespan and family perspectives. New York: Holt, Rinehart and Winston Inc.

Corless, I. B., Germino, B. B and Pittman, M. (1994). Dying, death and bereavement- theoretical perspectives and other ways of knowing. Boston: Jones and Bartlett Publishers.

Dane, B. O. and Miller, S. O. (1992). AIDS- intervening with hidden grievers. Connecticut: Auburn House.

Doka, K. (1989). Disenfranchised grief- Recognizing hidden sorrow. Washington: Lexington Books.

Ernst, C. and Angst, J. (1983). Birth order. Its influence on personality. New York: Springer-Verlag.

Fogarty, J. (2000). The magical thought of grieving children, treating children with complicated mourning and advice for parents. New York: Dyewood Publishing Company.

Freiherr Von Manteuffel, K. (2005). An introduction to grounded theory. Retrieved 14 January 2005 from the World Wide Web: Indoglobal.com web services.

Freud, S. (1957). Mourning and melancholia. In J. Strachey (Ed. And Trans), The standard edition of complete psychological works of Sigmund Freud 14, 237-258. London: Hogarth Press and the Institute for Psychoanalysis (Original work published 1917).

Freud, S. (1950). Mourning and melancholy, collected papers, vi. London: Hogarth TH press.

Glaser, B. G. (1992). Basics of grounded theory: Emergence versus force. Mill Valley: Sociology.

Glaser, B. G. and Strauss, A. L. (1967). Discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine.

Glaser, B. G. and Strauss, A. L. (1974). The Discovery of grounded theory. Chicago: Aldine Publishing Company.

Glaser, B.G. (1998). Doing grounded theory: Issues and discussions. Mill Valley: Sociology Press.

Goldman, A. (Ed). (1994). Care of the dying child. Oxford: Oxford University Press.

Greve, W. (April 2001). Traps and gaps in action explanation: Theoretical problems of a psychology of human action. Psychological Review. 108.

Grollman, E. A. (Ed). (1995). Bereaved children and teens: a support guide for parents and professionals. Boston: Beacon Press.

Harvey, J. H. (2002). Perspectives on loss and trauma- Assaults on the self. California: Sage Publications.

Holloway, I. and Wheeler, S. (1996). Qualitative research for nurses. London: Blackwell Science Ltd.

Illson, R., Crystal, D., Wells, J. C., and Hill, L. T. (1988). Readers digest universal dictionary. New York: Springer.

Jackson, E. N. (1985). Understanding grief. London: SCM Press Ltd.

Kalish, R. (Ed). (1980). Caring relationships: The dying and the bereaved. New York: Baywood Publishing Company.

Kaplan, D. M. (1971). Coping with childhood leukaemia- A severe family crisis, part one. Unpublished paper, Stanford university school of medicine, 1-18.

Kaplan, H. I. and Saddock, B. J. (Eds). (1995). Comprehensive textbook of psychiatry 6th ed. Baltimore: Williams and Wilkins.

- Kastenbaum, R. (2000). The psychology of death 3rd ed. London: Free Association Books.
- Kavanaugh, R. E. (1974). Facing death. Baltimore: Penguin books.
- Knapp, R. J. (1986). Beyond endurance when a child dies. New York: Schocken Books.
- Kock, N. (2002). Three threats of action research: A discussion of methodological antidotes in the context of an information system study. Retrieved 26 August 2003 from the World Wide Web: <http://www.sciencedirect.com.raulib.ac.za>.
- Kubler-Ross, E. (1969). On death and dying. London: Macmillan.
- Kurstak, E., Lipowski, Z. J. and Morozov, P. V. (Eds). (1987). Viruses, immunity and mental disorders. New York: Plunem Medical Book Company.
- Lewis, J. (2002). Mobilising Gender Issues. Oslo: The Nordic institute for women's studies and gender issues (NIKK).
- Lovelife. (2001). Impending catastrophe revisited – an update on the HIV/AIDS epidemic in South Africa. Parklands: Kaiser Family Foundation, DGR writing and research.
- Matinson, I.M., Gillis, C. and Colaizzo, D.C. (1990). Impact of childhood cancer on healthy siblings. Cancer Nursing, 13, 183-190.
- Miller, D., Weber, J. and Green, J. (Eds). (1986). The management of AIDS patients. London: Macmillan.
- Miller, W. and Crabtree, B. (1997). Doing qualitative research. Sweden: Sage publishers.
- Mouton, J. (1998). Understanding social research (2nd ed). Pretoria: Sigma Press.

- Munhall, P. L. (1998). Design in nursing research (2nd ed). California: Sage Publishers.
- Nagera, H. M. D. (1970). Children's reactions to the death of important objects: A developmental approach. The Psychoanalytic Study of the Child, 25, 360-400.
- Nagy, M. (1936). The child and death. Budapest: Brenz.
- Natterson, J. N. and Knudson, A. G. (1960). Observations concerning fear of death in fatally ill children and their mothers. Psychosomatic Medicine, 22, 456-463.
- Nisbett, R. E., Peng, K., Choi, I. and Norenzayan, A. (April 2001). Culture and systems of thought: Holistic versus analytic cognition. Psychological Review, 108, 2.
- Parkes, C. M. (1986). Bereavement: Studies of grief in adult life. New York: International Universities Press.
- Parkes, C. M., Laungani, P. and Young, B. (Eds). (1997). Death and bereavement across cultures. London: Routledge.
- Petrillo, M and Sanger, S. (1972). Emotional care of hospitalised children. PA: Rodale Press.
- Population Council (2001). Reducing HIV infection among youth: What can schools do? Baseline data from Mexico, South Africa and Thailand reveal a complex picture of behaviour and attitudes among students. Retrieved 2 April 2002 from the World Wide Web: Horizons report.
[http://www.popcouncil.org/horizons/newsletter/horizons\(3\)_1.html](http://www.popcouncil.org/horizons/newsletter/horizons(3)_1.html).
- Randoo, T. (1993). Treatment of complicated mourning. Illinois: Research Press Publications.

Raphael, B. (1985). The anatomy of bereavement – a handbook for the caring professional. London:Hutchinson.

Reber, A. S. (1988). The penguin dictionary of psychology. London: Penguin Books.

Roos, S. (2002). Chronic sorrow. A living loss. New York: Brunner-Routledge.

Russel, M. (2000). A rapid appraisal of community-based HIV/AIDS care and support programs in South Africa. Retrieved 1 June 2003 from the World Wide Web: HST. <http://www.hst.org.za/research/hivsupp.htm>.

Spinetta, J. (1984). Measurement of family function communication and culture effects. Cancer, 53, 2230-7.

Saurkes, B. (1987). Siblings of a child with a life threatening illness. Journal of Children in Contemporary Society, 19, 159-184.

Schoenberg, B., Carr A. C., Peretz, D. and Kutscher A. H. (Eds). (1970). Loss and grief- psychological management in medical practice. New York: Colombia University press.

Stern, P. N. Eroding grounded theory. (1994). In J. M. Morse (Ed.). Critical issues in qualitative research methods (pp. 212-223). London: Sage.

Strauss, A. and Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques. London: Sage.

Strauss, A. and Corbin, J. (1994). Grounded theory methodology: An overview. In N. K. Denzin and Y. Lincoln (Eds.), Handbook of qualitative research (pp. 73-91). Thousand Oaks, CA: Sage.

- Strauss, A. L., and Corbin, J. (1998). Basics of qualitative research: Techniques and procedures for developing grounded theory (2nd ed). London: Sage.
- Stroebe, M. S., Hansson, R. O., Stroebe, W. and Schut, H. (Eds). (2001). Handbook of bereavement research – consequences, coping and caring. Washington: American Psychological Association.
- Thomas, K. A. (1990). Time series analysis-spectral analysis and the search for cycles. Western Journal of Nursing Research, 12, 558-562.
- Van Dyk, A. (2001). HIV/AIDS care and counselling- a multidisciplinary approach (2nd Ed). South Africa: Pearson Education.
- Walter, T. (1999). On bereavement- the culture of grief. Buckingham: Open University press.
- Weiss, R. A., Adler, M. W. and Rowland-Jones, S. L. (Eds). (2001). The changing face of HIV and AIDS. Oxford: Oxford University Press.
- Wilson, H. S. (1985). The craft of qualitative analysis from observation to exploration in qualitative research in nursing. Menlo Park: Addison – Wesley Publishing Company.
- Wolfelt, A. (1988). Death and grief a guide for clergy. Indiana: Accelerated Development.
- Wolfelt, A. (March/April-1991). Towards an understanding of complicated grief. The American Journal of Hospice and Palliative Care, 6, 28-30.
- Wolfenstein, M. (1966). How is mourning possible?. Psychoanalytic Study of the Child. 21, 93-123.
- Worden, W.J. (1982). Grief counselling and grief therapy- a handbook for the mental health practitioner. New York: Springer.

Worden, W.J. (1991). Grief counselling and grief therapy (2nd ed). New York:
Springer.

Appendix one.

Interview Questionnaire.

Sherona Rawat.

Bereavement.

Interview schedule.

Tell me a little about yourself?

Name (optional): _____

Age: ____ Sex: M F

Marital status: married/divorced/separated/living together/single/widowed/remarried (no. times)

Length of marriage: _____

No. of children: _____

Name	Age	Sex	Level of schooling	Living with parent/s	Not living with parent/s

Have you ever been hospitalised for psychological problems? Yes No

If yes, when and where?

Tell me a little about your child, your experience of his/her death and how you have coped thus far?

Bereavement.

1. Name of deceased child:- _____

2. Child's age at death:- _____ Gender:- M F

3. Where you told about your child's illness and the chances of his/her surviving? _____

4. When did you realize that your child would not survive? _____

5. How should a woman behave when she is mourning the death of her child? _____

6. How should a man behave when he is mourning the death of his child?

7. How did you feel when he/she died?

8. How do you feel now?

9. (Will people behave differently towards you if they know that your child died from HIV/AIDS?) _____

10. (Have you told anyone that your child has died from HIV/AIDS?) _____

11. (Who?) _____

12. (Is an AIDS related death treated differently from other deaths?) _____

13. (How?) _____

14. Has any other loved one passed away within the last two months?

15. When?

16. Who? - Spouse friend family member
(specify) _____

17. What did he/she die from?

18. How did you feel about that death?

19. How do you feel now?

20. Describe the death rituals that you have to perform?

21. (Is it different for AIDS related deaths?) _____

22. Describe the grieving process?

23. (Is it different for AIDS related deaths?) _____

24. What do you think is the best way to handle the loss of your child?

25. Do you feel that there was anything you could have done to prevent the death?

26. How is your spouse handling the death of your child?

27. How are your children handling the death of their sibling?

28. Has the death of your child changed your relationship with your remaining children?

29. If yes, How?

30. Has the death of your child affected your relationship with your spouse? _____

31. If yes, How?

Tell me a little about your family and how they have helped you cope with the death?

Support.

32. Is there anyone that you can talk to when you need support?

33. Who can you really count on to support you in major decisions or plans?

34. Who can you count on to console or comfort you when you are very upset?

35. Who could you trust with a secret or information that could get you into trouble?

36. Who do you feel truly loves you deeply?

How do you feel now about the loss of your child?

Adaptation.

37. Do you think that there is anything a person can do to prevent getting sick?

38. Are there any specific behaviours, actions or habits that you would like to change?

39. What will your friends/family think of this new behaviour?

Mental/psychological health.

40. Have you experienced any of the following (physical) symptoms since the death?

Chest pains, headaches, itching, constipation, heart pounding or racing, nausea or upset stomach, diarrhoea, stomach pain, hair loss, skin rash, blurred vision, slurred speech, vomiting, loss of weight, gaining weight, faintness or dizziness, a lump in your throat, numbness or tingling in parts of your body, heavy feeling in your arms or legs, skin rash.

41. Have you experienced any of the following (psychological) symptoms since the death?

Nervousness or shakiness inside, unable to get rid of bad thoughts, loss of sexual interest or pleasure, feeling critical of others, bad dreams, trouble remembering things, feeling irritated or annoyed, tired, thoughts of ending life, sweating, trembling, feeling confused, poor appetite, (crying easily), fearful, anxious, feeling trapped, feeling lonely, loss of interest, worrying, overly sensitive, paranoid, difficulty in falling asleep, difficulty in staying awake, lack of concentration, wanting to be alone, feeling hopeless about the future.

42. Life experiences childhood/adolescence:

Happy childhood/ unhappy childhood

Emotional / behavioral problems

Legal problems

School problems

Family problems

Strong religious convictions

Drug abuse

Medical problems

Alcohol abuse

Behaviour: (according to spouse when asked to describe their spouse's

behaviour)

Overeat	Suicidal attempts	Can't keep a job
Take drugs	Compulsion	Insomnia

Vomiting	Smoke	Take too many risks
Withdrawal	Drinking too much	Concentration difficulties
Odd behaviour	Dating problems	Sleep disturbances
Work too hard	Aggressive behaviour	Outbursts of temper
Crying	Impulsive reactions	
Lazy	Procrastination	
Loss of control	Nervous tics	
Phobic avoidance		

43. Is there anything else that I might have missed that you would like to mention?
