

# **THE MEANING OF PARENTAL BEREAVEMENT**

by

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Submitted in partial fulfilment  
of the requirements for the degree

**M.A. (PSYCH.)**

in

**PSYCHOLOGY**

in the

**FACULTY OF ARTS**

at the

**RAND AFRIKAANS UNIVERSITY**

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October, 2002

## **Abstract**

An investigation of existing research literature was undertaken to explore the experience of bereavement of parents whose child has died. The review comprises an overview of theoretical approaches to bereavement and the various factors which determine the grief experience. These include an examination of factors surrounding the loss, personal factors and coping skills, as well as an outline of familial, cultural and social aspects. A further focus of the review, is on the process of meaning making in the aftermath of a traumatic event, such as parental bereavement following on the loss of offspring. A particular focal point in this respect is the exploration of how the experience of parental bereavement motivates the search for meaning and the possible significance of this meaning in the continued life of the bereaved parent.

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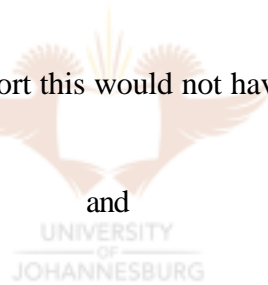
# Dedication

To my husband

Terry

and our children,

without whose support this would not have been possible



and

in loving memory of Julie-Anne

(9.10.1978 - 19.2.1979)

## Acknowledgement

I am grateful to my supervisors for their enthusiasm and direction. I am especially indebted to Professor Pretorius for her unstinting support, constructive reviews and pertinent suggestions.

My thanks also go to the Johannesburg chapter of The Compassionate Friends for allowing me access to their many resources and also to Madge Rix for her continued encouragement and assistance.



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# **1 Foreword**

The bereavement process has been much studied in the last quarter century. However, much of the interest was initially directed at spousal loss and it is only relatively recently that the focus has begun to be directed at parental bereavement through loss of a child. In contrast to many previous pandemics, AIDS afflicts primarily adults and young adults, at a time in their lives when their parents are still expected to be alive. It is likely then, that a greater proportion of parents is facing the loss of adult children than has been the case heretofore. In addition, it appears that losing a child as a result of an AIDS-related illness may be a more difficult loss, because of the confluence of factors that are likely to complicate the bereavement process and also because of the stigmatising nature of the illness. In light of this, a greater understanding of parental bereavement would serve a useful purpose.

The search for meaning appears to be a central aspect in humanity as is evidenced from long past mythologies and early written texts to current philosophical endeavour. The loss of a sense of meaning in life creates a sense of inner desolation and spiritual barrenness that spurs the search for meaning. The experience of bereavement has been linked with the search for meaning as individuals seek to understand what has occurred and make sense of a world that does not conform to previously-held convictions.

## **1.1 Aims of the mini-dissertation**

The aim of this mini dissertation is to acquire a fuller understanding of the field of parental bereavement through an exploration of the literature which has been published in this field and a subsequent integrative analysis of such literature. Another area of exploration is that of the process of meaning making, especially in regard to the aftermath of a traumatic event such as parental bereavement following on the loss of offspring. The focus is particularly on exploring how the experience of parental bereavement can motivate a search for meaning, and also on exploring the significance of such a search for meaning.

## 1.2 Definitions of terminology

The use of terminology pertaining to bereavement, grief, mourning and loss in the literature can be confusing as these terms are used interchangeably. In order to ensure clarity, for the purposes of this study, the term **bereavement** refers to the occurrence of the loss of someone with whom there is a close relationship and the reaction of the bereaved person to the loss. The state of having suffered a loss is bereavement. According to Rando (1993) the etymological origin of the word **bereavement** shares a root with "rob" which is descriptive of the shared sense of deprivation against one's will.

**Loss** is defined as an event that leads to the permanent unavailability of a person or object that is emotionally significant to an individual and to which the individual was attached (Martin & Doka, 2000). Loss always results in deprivation of some kind and generally losses are perceived as being unp.

A griever may also experience secondary losses which are the physical or symbolic losses that develop as a consequence of the death of the loved person. This is as a result of changes to relationships with other family members, loss of activities that were linked to the deceased and other experiences in the life of the bereaved on a day-to-day basis. Where the understanding of one's role in life changes, such as a change of self-perception from adequate parent to inadequate parent, a symbolic loss may be experienced.

Loss is concomitant with change as each transition, whether pleasant or not, involves some loss. For instance, even where marriage follows on a happy decision, it entails the loss of some freedom. The meaning of loss differs from person to person and it is the idiosyncratic meaning of the loss which influences the grief reaction.

Stroebe and Stroebe (1992) propose that the terms **bereavement** and **grief** be differentiated, with **bereavement** referring to the objective situation of an individual who has recently experienced the loss of a significant person through death, and **grief** referring to the emotional response of the individual to such a loss. Worden (1988) also defines grief as the personal experience of loss. Grief includes sadness,

anger, guilt, despair and hopelessness and constitutes a part of the bereavement process. Parkes (1988) notes that awareness of the difference between how things are, and how they were, or should be, triggers grief. In this sense grief is a natural occurrence consequent upon loss and forms a complex and coherent pattern of reactions. These include psychological reactions, which include feelings, thoughts and attitudes; social reactions (interactions with others) and physical reactions with attendant bodily symptoms (Kleber & Brom, 1992).

The terms **grief work**, **mourning** and **grieving** are often used to denote the process which occurs following a loss. Using the term **grief work** (Lindemann, 1944) illustrates the active nature of the grieving process highlighting that there are tasks and processes to be completed in order to resolve the grief. The terms also refer to the conscious and unconscious processes that gradually undo the psychological ties that bind the bereaved to the deceased, thereby facilitating adaptation to the loss (Rando, 1988). As part of the work of grieving, the bereaved person mourns not only the actual deceased person and the needs that they fulfilled, but also the hopes, expectations, ambitions and dreams held in connection with the deceased. Self-identity needs to be redefined as well as the assumptive world of the bereaved person. Martin and Doka (2000) reflect that current thinking emphasises the continued connection of the bereaved person to the deceased although the nature of the connection changes, finding expression in memories, legacies and spiritual beliefs.

**Meaning**, for the purposes of this study, refers to the exploration of the purpose and significance of the existence of the individual. According to Frankl (1964a) the search for meaning is unique for each individual and constitutes a primary motivational force in the existence of that person. It is precisely and exclusively the unique nature of the definition of meaning for the individual that provides a satisfactory response to a search for meaning. Not only are individuals driven to seek meaning in their lives, but there is also "a desire for a life that is as meaningful as possible" (Frankl, 1964a, p.100).

According to Fabry (1967), a phenomenological analysis demonstrates that meaning can be found in the creation of something of merit. The experiences that life



proffers, including those that are painful or that cause suffering, are rich with meaning as is the knowing, respecting and appreciating of the value of others. Grappling with issues of meaning is thus a central precept that enables an individual to relate, not only to the present, but also directs the individual towards the future.

### **1.3 Methodology**

The methodology for the mini-dissertation is a literature review which explores the issues of bereavement with a special focus on parental bereavement. The death of the child as a result of AIDS, which is a stigmatised illness, is of particular interest. Furthermore, the literature review explores the issue of meaning-making with the aim of integrating this knowledge with the circumstances surrounding parental bereavement.

It is proposed that the mini-dissertation will form the basis for further doctoral research. As such, it will constitute Chapter 2 of this proposed future thesis.

## **2 Chapter 2**



### **2.1 Bereavement**

#### **2.1.1 Introduction**

The experience of loss is ubiquitous to humanity. Sometimes loss happens with unexpected suddenness, at other times it occurs slowly and with insidious finality. Some losses are bearable, others wrenching in their impact and the enormity of some losses has the capacity to change those who have suffered the loss. The pain of the loss of someone who is loved is difficult to deal with because it is an irretrievable loss and so the experience of loss is profound because of its life-altering quality.

"Give sorrow words: the grief that does not speak whispers the o'erfraught heart, and bids it break." (Shakespeare, Macbeth, Act IV, Scene iii). In his autobiographical account of the loss of his wife, Lewis (1978) has indeed attempted to give sorrow words. He describes how he believed it would be possible to describe the state of loss and 'make a map of sorrow' (p.47). He finds however that it is not a state but a

process, not a map but a history. It describes the landscape of grief, constantly changing yet echoing past experience. The volumes that have been written on the subject of loss bear testimony to the injunction to give sorrow words. Perhaps it is in doing this that people are able to find a meaning that makes sense of their loss.

### **2.1.2 Patterns of Grief**

Many patterns of grief have been observed and described in the literature. Littlewood (1991) describes a wide range of somatic symptoms that may occur in grief, though these are not necessarily experienced by everyone equally. These include a sense of hollowness in the stomach or abdomen, a sense of tightness in the throat, chest and shoulders, dry mouth, muscular weakness, fatigue, tiredness and lack of energy, frequent sighing and breathlessness. Oversensitivity to light and noise stimuli is also a common experience. Other symptoms frequently include appetite and sleep disturbances, visual and auditory hallucinations and dreaming of the dead person.

The impact of the physical nature of the symptoms is confirmed in various studies: Holmes and Rahe (1967) found that loss of a spouse has the highest life stress rating. From an historical perspective, grief was accepted as a cause of death Dr Heberden's 1657 Bill classifying the causes of death in London listed causes such as flox, small pox, gout, griping, suicide and "griefe", and many bereaved people do in fact seek medical advice after a bereavement (Parkes, 1972). Stroebe, Stroebe and Domittner (1988) confirm that the risk of suffering a variety of ailments is significantly raised for a considerable period of time following a bereavement. This could be attributed to the fact that raised levels of corticosteroids are common during periods of active mourning, which includes anniversaries of the death or birthdays of the deceased.

Hafen, Karren, Frandsen and Smith (1996) conclude, on the strength of various studies, that parents who lose children are at a particular risk for illness, especially where this is coupled with being divorced or being widowed. The brunt of the loss which manifests in these physical symptoms is also evident in the increased mortality and morbidity rates of bereaved people: research carried out at the Mount Sinai Hospital in New York indicates that of the people who die within a year of losing a spouse, 20 percent die as a direct result of the loss.

The range of emotional experiences described by Littlewood (1991) includes shock, numbness and disbelief. A sense of anxiety is exacerbated by fears of feeling unsafe, or of being alone and of being overwhelmed by grief. Fears of becoming insane are made worse by confusion and an inability to concentrate. There may be preoccupation with thoughts of the deceased and the events leading up to the death, especially where there is a lack of clarity over what led to the death. Sadness is a pervasive emotion even when it is not associated with crying. The extent of crying is not necessarily indicative of the intensity of the grief, especially when social or cultural constraints are considered. For example, it may be less acceptable for men to cry, and this is especially more so after the first short period after the loss. Anger, too, is commonly experienced, and can be directed at the self, those believed to be responsible for the death, society, fate and God. There is often a sense of guilt, especially over acts or omissions, even if these are not necessarily based in reality. Other feelings include loneliness, restlessness, apathy, a yearning to be with the deceased person and searching for them. Despair and a sense of meaninglessness of life and living can contribute to a desire for life to end and suicidal ideation is not uncommon.

Worden (1988) describes some common thought patterns or cognitions of the newly bereaved person, some of which may trigger feelings that lead to depression or anxiety if they persist for a considerable period of time. Disbelief is generally the first thought on being faced with the news, and this gives way to a sense of confusion where concentration is impaired. There may be a preoccupation with thoughts of the deceased which may include obsessional thoughts on how to retrieve the deceased. Another common thought pattern is the belief that the deceased is somehow still present. Visual and auditory hallucinations may also occur, normally in the first few weeks following the loss.

Worden (1988) has also enumerated various specific behaviours which are associated with a grief reaction. As described earlier, sleep and appetite disturbances are common. The newly bereaved person may behave in an absent-minded way, thereby causing themselves inconvenience or harm. Social withdrawal is also common and can include a loss of interest in events outside. Other common behaviours are

dreaming of the deceased, searching and calling out, restlessness and hyperactivity, crying and sighing, and visiting places or carrying objects that are reminiscent of the deceased. Martin and Doka (2000) have also added the following possible changes from preloss behaviours: increase in the use of alcohol, smoking or other chemical use, in order to alleviate anxiety or depression, as well as observable changes in religious or spiritual behaviours and accidents.

Shapiro (1994) finds that the initial response to bereavement is overwhelmingly physiological. Symptoms described often refer to a chronic pain located in the chest, and difficulties in breathing and swallowing. Sleep and appetite disturbances are prevalent, as is a decline of the immune response. Initially there is a sense of unreality followed later by a sense of divided consciousness, as there is a refusal to believe the news of the death on one level, though understanding about it on another.

Worden (1988) construes the function of the mourning process as being task orientated. The first task is to accept the reality of the loss. As the searching fails to retrieve the deceased, continued searching behaviour, as described by Bowlby and Parkes (1972) is geared towards the facilitation of this first task. During this time, denial, varying from distortion to full-blown delusion, can persist as a form of protection against the full impact of pain which would result from a fuller acceptance of reality. This can present in various ways such as a denial of the meaning of the loss, selective forgetting or a denial of the irreversibility of the loss.

The second task is to experience the pain of the grief. In this regard, Parkes (1972) contends that where the emotional and behavioural pain of grief is avoided or suppressed, the mourning process is drawn out. Strategies to avoid the pain can be to avoid thinking about it either by thought-stopping or replacing unpleasant thoughts by more pleasant ones such as idealising the deceased. Other strategies involve changing the environment or moving. (Worden, 1988).

The third task is to adjust to an environment without the deceased. Having to develop new skills and take on new roles may form part of this task. Friends, relatives or colleagues may feel resentful of the bereaved person, believing that they are refusing to adapt to the loss by promoting their own helplessness. The final task

for the bereaved person is to withdraw emotional energy from the deceased and reinvest it in another relationship. Worden (1988) suggests that this may be the most difficult task to achieve, as the prospect of reinvestment can be a frightening one in the light of the bereaved person's sense of vulnerability to pain following attachment.

### **2.1.3 Theories of bereavement**

Although an integrated theory of bereavement has not yet been achieved, several theories have attempted to explain this phenomenon. According to Freud (1991), normal grief is the person's reaction to the loss of a loved one which may be resolved after unspecified time and after serious departures from everyday life. A person's libido is attached (cathected) to the loved object: the beloved person and their loss requires all thoughts about the deceased person to be brought to consciousness in order for the libido to be detached from them (decathected). The mourner's struggle to maintain the original attachment means that completing this grief work, or catharsis, is long, difficult and painful, hence the term 'grief work'. Decathexis ensures that the love object does not offer gratification to the bereaved person any more, and that the libido is freed for investment in a new attachment object.

In his seminal work "Mourning and melancholia", Freud (1991) differentiated between normal mourning and its pathological counterpart, which was termed 'melancholia'. While melancholia resembles grief, it is initiated by psychological object loss rather than the actual loss of the beloved. The inability or refusal to relinquish the love object may result from narcissistic or ambivalent attachment where the love object is both loved and hated. Remorse, guilt and self-criticism are a way for the ego to express this ambivalence. Although the differentiation between normal and abnormal grief seems to have given rise to seeing grief as an illness, according to Freud the human psyche is adequately equipped for accomplishing the bereavement process, which is a crucial task, irrespective of its duration.

Lindemann (1944) in his classic study of the survivors of the Coconut Grove nightclub fire in Boston, described the symptoms exhibited by this group. These included somatic symptoms including pain in the chest; shifts of sensory perception (for some people auditory or visual hallucinations of the deceased); preoccupation with the deceased; disruption of normal day-to-day activities; and emotions such as guilt and

hostility. His conclusion that the acute symptomatology as well as the grief process could be resolved within four to six weeks, however, has not been borne out by researchers in subsequent studies (Parkes, 1988; Rando, 1986; Weiss, 1988; and Wortman & Silver, 1989). Moreover, Shapiro (1994) quotes the case of one survivor of the Coconut Grove fire who, on being interviewed once again about her experience of the fire in 1989, has described her continued grief and flashbacks.

Since Freud, the object relations approach has been a major development in psychoanalytic theory, with the focus on the interpersonal relationships that people develop so that the objects of desire in object relations are people, rather than targets of libidinal drive, as in Freudian theory (Cashdan, 1988). Arguing from an object relations perspective, Rubin (1999) suggests that the internal representations of others, while based in reality, are also influenced by internal object schemata. It is these internal representations that affect the perceptions and interactions of the individual. However, after the death of a person who is significant to the individual, interactions in the real world come to end as regards any present and future relationship between the bereaved and the deceased. This means that any further interaction with the deceased person moves solely into the realm of the internal world of the bereaved. Secondly, the representation of the deceased in the world of the bereaved person affects their self-perception, affective functioning and psychological well-being. In an effort to manage the internal equilibrium of the individual's self-image, memories and past relationships are being continually reworked at both conscious and unconscious levels.

For this reason, Rubin (1999) suggests that it is not sufficient to look at function, and that the quality of the recollected and remembered relationship with the deceased must also be acknowledged. In his Two-track model of bereavement (Rubin, 1981), the bereaved person's functioning is taken into account, as well as the nature of the continuing attachment to the deceased, thus separating the analysis of personality function from the object detachment aspect of the bereavement process. Aspects of the continuing relationship with the deceased that must be considered include: imagery and memory; emotional distance; positive and negative feelings in respect of the deceased; preoccupation with loss; idealisation; conflict; shock; searching; disorganisation and reorganisation. The goal for true recovery from bereavement

thus requires a new integration of the internalised relationship of the bereaved person with the deceased. This relationship continues to exist as a valuable inner resource, though not detracting from the capacity of the bereaved to establish or continue other relationships with the living.

According to Bowlby (1969) grief is essentially separation anxiety following on an unwanted separation from an attachment figure and follows on his work that examines childhood separation responses. In the case of children, a threat of separation from the caretaker or mother evokes a range of responses, the most common of which are crying, protest and searching for the lost attachment figure. The magnitude of this reaction depends on the potential for loss in the situation. Attachments form in respect of specific others, and last for a large part of a person's life. These bonds, or attachments, develop early in life and are a consequence of a need for safety and security. The goal of attachment behaviour is the maintenance of the attachment bond between the individual and specific others and in an evolutionary sense, it has survival value. According to Worden (1988), there is evidence to support the contention that all human beings grieve loss in an effort to be reunited with their attachment object.

The same principle underlies attachment bonds to spouses and children, hence the similarity of the grief reactions as evidenced by adults to the reaction to separation experienced by children (Bowlby, 1969). Initially there is brief period of protest at the separation, before searching behaviour occurs. As the individual realises that these fail at restoring the lost attachment figure, despair and depression follow. When considered in the context of the grief process, he maintains that separation does not signify an end to the relationship with the deceased person, and that part of the task of restructuring is to include a sense of the deceased person into the sense of self. Indeed, there is a phase of reorganisation during which time the individual restructures their situation in a cognitive sense.

Bowlby suggests, and Weiss (1988, p.43) agrees, that "all the emotional systems underlying the attachment relationships of adult life will eventually be shown "to be derived from the emotional system underlying attachment in children." Weiss (1988) notes that grief does not necessarily follow every loss experienced by a person. For

instance, the loss of a colleague may evoke sadness and a sense of diminished community but will not result in the protracted distress of grief which is characterised by numb disbelief, searching and pining, and depression. The characteristics of those relationships which tend to produce grief reactions by their loss, are those where:

- The presence or availability of the attachment figure fosters a sense of security.
- If the attachment figure is not present or available, a belief of being reunited with the attachment figure can also foster a sense of security.
- Conditions of threat or danger cause the attachment feelings and behaviours to emerge.
- If reassuring contact cannot be re-established separation distress follows. This is characterised by searching behaviour, a sense of apprehension and anxiety, as well as vigilance and an inability to focus on other matters.
- The attachment figure is unique and it is not possible to substitute someone else for them.
- The distress following separation cannot be removed through strategies such as distraction, as it is not under conscious control.
- Attachment to specific people does not diminish with habituation.
- Attachment persists regardless of the nature of the experience of relationship with the attachment figure.

Like Freud's theory, Bowlby's attachment theory (1969) is also a cathexis theory demonstrating how the childhood bond plays a crucial role in later relationships and stresses the instinctual and congenital aspects of the grief process. In a marked departure from Freud however, Bowlby contends that mourning is not a pathological process (unless it is suppressed or delayed) and that the relationship with the deceased does not cease in healthy bereavement. Moreover, the continued sense of presence of the deceased is of comfort to the bereaved person and is helpful in the cognitive restructuring of the life of the bereaved person.

As in many of the later psycho-analytic approaches to bereavement, the idea that grief is determined by intrapsychic processes remains a central tenet: in the models proposed by Bowlby and Parkes (1972), cognitive functioning and goal-orientedness



in adaptation are stressed. According to Parkes (1972), the restructuring that occurs during the grief process enables the bereaved person to re-acquire a sense of control over life so that recovery from bereavement is marked by the attainment of a new level of functioning. As in Bowlby's approach, the theory is to some extent cathartic and views grief as separation anxiety. The model is a medical one and attempts to classify grief in terms of a medical diagnosis.

Two important factors serve to differentiate Parkes' theory and highlight the psychosocial aspect of bereavement. Stigma refers to the attitude of society to the bereaved person while deprivation refers to the absence of those psychological benefits which the deceased had provided to the bereaved person during their lifetime. These factors also play a significant part in the overall outcome of the grief process. Recognition of these psychosocial factors can be important when providing therapeutic intervention to parents as they may exacerbate the intensity of the grief process.

In contrast with the psychoanalytically-oriented models, behaviourally-oriented theories tend to view grief as a natural phenomenon which can be reinforced or inhibited by external stimuli rather than by intrapsychic processes. Their approach is characterised by a more clinical viewpoint with a focus on abnormal or pathological grief processes and intervention strategies. Empirical evidence for these approaches, however, is limited (Corr, 1979). Ramsay (in Cleiren, 1991), a proponent of this approach has emphasised the role of reinforcement, and environmental factors such as social support. Gauthier and Marshall (in Cleiren, 1991) have also stressed the importance of social environment in conjunction with disposition, abruptness of the loss and its significance to the bereaved person.

Crisis theory (Moos, 1986) has been shaped by various approaches that attempt to provide an understanding of life crises: evolutionary theory; psychoanalytic concepts about personal fulfilment and growth; a developmental life-cycle perspective and information on the process of coping. It examines the general determinants of outcome of a "situation so major that habitual responses are not sufficient" (Moos, 1986, p.6). Crises provide the momentum to develop new cognitive and personal skills in order to ensure effective adaptation and as such may be an essential

condition for psychological development. Five major adaptive tasks have been identified in managing a crisis:

- To establish the meaning of the situation and to understand the personal significance of the situation. After the initial stage of shock and confusion, the individual is faced with assimilating the event and its aftermath. In the case of death, there is a need to accept the loss intellectually, and also to explain it.
- To confront reality and respond to the requirements of the external situation.
- To sustain relationships with family members, friends and others who can be of assistance in resolving the crisis and its aftermath. It is paradoxically at precisely the time when the support of close personal relationships is most necessary as a source of emotional support in a period of crisis that it can be most difficult to achieve this and find or maintain such relationships.
- To preserve a reasonable emotional balance by managing upsetting feelings aroused by the situation. Guilt, a sense of failure, self-blame and anger are common emotions following the death of a child. The ability to sustain hope is important in coping with depression.
- To preserve a satisfactory self-image and maintain a sense of competence and mastery. Changes in the life circumstances of the individual must be assimilated so as to produce a revised self-image. This 'identity crisis' may require a shift in behaviour or values. Rando (1983) found that the best coping styles of bereaved parents were active and externally directed and comprised altruism or altruistic activities.

A variety of emotions is experienced when facing a crisis, and the attribution of meaning follows later in the experience. As Moos (1986) notes, some crises are more challenging than others, and the death of a child is one of the most profound losses because of the unique parent-child bond.

A number of researchers have questioned the validity of traditional theoretical frameworks in understanding the grief process: Bonanno, Keltner, Holen and Horowitz (1995), Harvey and Miller (2000), Nolen-Hoeksema, McBride, and Larson (1997) Stroebe and Stroebe (1991) as well as Wortman and Silver (1989) have all failed to find evidentiary support for traditional perspectives on grief and loss.

In light of the importance of these findings, it is suggested that it is surprising that alternative views are not more widely represented in the literature. Neimeyer (2001) argues that the accumulation of evidence from clinicians who have worked in this field is in direct contradiction of the Freudian perspective. Instead, he believes that the evidence thus gathered fits more accurately the post-modern perspective which gives due importance to the power of subjectivity in the lives of people. He suggests therefore, that as a result of this evidence, a paradigm shift is occurring among practitioners and theorists within this field, and that this shift mirrors the profound alteration of worldview that the bereaved individual experiences in making sense of the loss.

Neimeyer (1998) also challenges the notion that resolution of grief is signalled by letting go of the deceased. Grief theory should be unique to each bereaved individual, with each individual seen as an active agent in the shaping of their world. This view of grief suggests that grief is essentially a process of meaning reconstruction and narrative revision. According to him "meaning reconstruction in response to a loss is the central process in grieving" (p.110). Three phases: avoidance, assimilation and accommodation are conceptualised as typical of a life-long grief-cycle. Prescriptive definitions that would classify any deviations as pathological are shunned. Instead, the rich description of experience, with personal and social meaning being central to the process, is preferred to prescription.

The act of retelling the story is a social one and through it the bereaved can step out of the isolation of grief. In this sense it can be understood as a dialectical challenge to balance the need to focus inward and the need to restore social connection. Through personal and communal rituals there is a possibility of self-transformation, as well as the conversion of the relationship between the bereaved person and their social world with the deceased to one where an ongoing connection to the deceased is possible. Grieving, then, is understood as a process of reconstructing the world of meaning and the relearning of the self (Neimeyer, 1998).

Rosenblatt (2000) concurs that evaluating bereaved people in terms of pathology can blind the researcher to the way that bereaved parents find healing. Instead he has considered the narratives of bereaved parents finding that these reflect the significant

themes of the experience. Common domains in the narrative include the dying process, the actual death, funerary rituals, religions and relationships. Areas that do not appear to become domains are the larger societal context of the death or relating the death or experience to current events. Apart from the common domains mentioned above, a chasm appears to form between the bereaved parents, the world as it was, and the world around them, originating from the devastating feelings experienced by the bereaved parents and the fragmentation and anonymity of society which means that few other people in society even know about the death. How to deal with this chasm constitutes a large part of what is said by bereaved parents.

Organising the narrative into a limited number of domains seems to promote a sense that it is possible to make sense of the event. Another explanation is that the number of culturally dominant domains offer a rhetoric which is meaningful and shared by others in constructing a reality that gives a sense of validity for themselves and others around them. In this respect then, these narratives are a product of the culture and time in which they are embedded. A grief theory is itself a narrative offering a low level empirical generalisation which does not account for the depth of the subjective experience.

In concluding, it appears that although a variety of theories has been developed, there does not appear to be a fully integrated theory of bereavement. Embracing only one theory, however, is limiting, to the extent that some relevant and necessary aspects in understanding the grief process would be overlooked.

#### **2.1.4 Stage Theories of Bereavement**

Bowlby (1969) has proposed four stages of mourning: numbness, yearning and searching, disorganisation and despair, and reorganisation. Numbness may last for a variable period of time, followed by a period of intense sadness. During this emotional time there may be feelings of rage, guilt and anger particularly where the relationship that has ended was ambivalent. Searching behaviour is also prevalent during this period that may last for periods of up to some years. The stage of disorganisation and despair is characterised by a sense of meaninglessness and a sense that life is not worth living. The detachment phase of separation, characterised by an acceptance of the loss and investment in new attachments, is echoed in the

final phase of mourning which is termed the reorganisation phase. Mourning ceremonies and rituals can facilitate the process by drawing in support from the community.

In a model influenced by Bowlby, Parkes (1972) also suggests four stages: shock, protest, despair followed by a long period of adaptation. The phase of shock offers a temporary moratorium from the pain of the loss and buffers the individual from experiencing the full impact of it. During the protest phase, the bereaved person attempts to 'retrieve' the deceased through a kind of 'magical thinking' ('if only something else had or had not been done or happened'). It is an intensely painful phase where the bereaved individual also experiences fear and anxiety with episodic bouts of panic.

The urge to search for the lost attachment figure can be understood in terms of the attachment feelings which are activated by the loss. The pain is exacerbated through the understanding that it is impossible to find the attachment object and this leads to a sense of despair, which is characterised by withdrawal and depression. Although the sequence of phases is generally in the order described above, this is not incontrovertibly the case.

Adaptation is characterised by cognitive and emotional acceptance of the bereavement and a change of identity. Central to the cognitive acceptance is that an individual develops a subjective understanding of the events surrounding the loss. Through a process of re-visiting the memories of the deceased, the emotionality associated with these memories is reduced to a level where the person is able to function without being overwhelmed by pain. Identity change requires that an individual develop a new understanding or image of themselves in a different relationship to the attachment figure. According to Weiss (1988) this aspect of recovery seems more difficult after the death of a child than after other significant losses, including loss of a spouse. Kübler-Ross (1974) in her research of the dying has proposed a model which roughly follows the same pattern as those proposed by Bowlby and Parkes. Five stages are posited in this model: denial, anger, bargaining, depression and acceptance.

In the phase model proposed by Rando (1993), the goal of the grief process is to adapt to the loss. In the avoidance phase the aim is the recognition of the loss which entails acknowledging that the death has occurred. The confrontation phase follows, characterised by the experience and expression of the psychological reactions to the loss and the identification of secondary losses. Other elements of this phase are remembering and re-experiencing the relationship with the deceased, and the letting go of the old attachment to the deceased and the old assumptive world. In the accommodation phase, readjustment is marked by an adaptive move into the new world that does not forget the old, and reinvestment in new relationship.

Zisook and DeVaul (1985) describe three stages of grief and the symptoms of typical grief as comprising:

- An initial period of shock, disbelief and denial. This stage is characterised by sighing and sobbing, tightness in the throat, a shortness of breath, an empty feeling in the abdomen, fatigue and restlessness with aimless activity and exhaustion, weakness and a sense of sorrow.
- An intermediate acute mourning period of acute physical and emotional discomfort coupled with social withdrawal. This stage is characterised by anger and irritability, an emotional distancing from people, avoidance of friends and/or work.
- A period of resolution where the attention of the bereaved person begins to return to the world around them once more.

Wortman and Silver, (1989) have questioned the value and usefulness for stage or phase models of bereavement, and very little evidence has been found to support this thesis in empirical research (Cleiren, 1991). Braun and Berg (1994) also believe that stage models are inappropriate as they fail to account for the lasting difficulty that some parents experience in the area of finding meaning in their child's death. This suggests that defining recovery as a return to a pre-loss state is inappropriate.

However, a more contemporary view, regards stage or phase models of bereavement as descriptive heuristic tools, rather than prescriptive rules (Stroebe, Van den Bout & Schut, 1994). According to this view, grief can be understood more as a process

where the early experience differs from that later on. Recovery can last an unspecified amount of time, although the intensity of the grief typically gradually diminishes. Feelings of grief may surface even years later in response to cues or stressful situations. The concept of recovery has also been questioned. Weiss (1988), for instance, suggests that a more correct terminology would be to refer to 'adaptation' or 'accommodation', rather than seeing an end-point to bereavement.

### **2.1.5 Determinants of grief**

There have been various attempts to determine what personal or other factors influence grief. (Rando, 1984; Sanders, 1988; Worden, 1988). For instance, the Harvard Bereavement Study (Parkes, 1972) attempted to identify what the significant determinants were in the way the grief process played out.

#### **2.1.5.1 Relationship of the deceased to the bereaved person**

The degree of consanguinity between the deceased and the bereaved is a significant determinant of the grief process so that the death of an acquaintance or work colleague is grieved less intensely than the death of a close family member. According to Arnold and Gemma (1994, p.9), "the loss of a child is a loss like none other" because it "signifies the loss of the future, of hopes and dreams, of new strength and of perfection". For this reason the loss of a child is believed to be the most difficult and significant adult bereavement (Arnold & Gemma, 1994; Cleiren, 1991; Sanders, 1988; Rando, 1986).

Moreover, the nature of the relationship is also important as regards the strength and security of the attachment. A relationship characterised by a small degree of attachment is easier to grieve than one characterised by a greater degree of attachment. According to Rando (1984) the type of role which the dead child filled and the function that they performed in relation to the bereaved, will be transformed after the death into important symbolic secondary losses, which also need to be identified and grieved. Another factor influencing the grief reaction is the amount of 'unfinished business' in the relationship between the child and the parent which are the issues that were never addressed or settled during the lifetime of the child.

Where the relationship is highly ambivalent, there may be a great deal of guilt and anger (Rando, 1984). Even where the relationship between parent and child had broken down prior to the death, there can be a sense of regret for the lost opportunities and the future loss of the possibility to re-establish a warmer relationship. Bowen (1978) notes that where the family is fused, family triangulation is common which implies some level of undifferentiation. The lower the level of differentiation, the more difficult becomes the process of separation. Where the relationship with the deceased had been characterised by anger or alienation, it may be difficult to acknowledge this aspect subsequent to the death (Kander, 1990).

The relationship of the child is one of the major constellations of meaning for the parent. Consequently the death of a child creates a major disequilibrium in the psychic structure of the parent which requires complex reorganization. The characteristics of the living relationship are part of the search for equilibrium after the death of the child. For instance, where the child is an inner representation of another relationship, the energy from that relationship is also invested in the relationship with the child (Klass, 1988). If the inner representations of the child within the parental psyche have a conflicted relationship, the task of separating these inner representations from one another may require purging the representation of stressful memories so that the representation can be an idealised one (Klass, 1988).

The unique constellation of characteristics which are joined in a specific child can make certain aspects of the grief more difficult. Death of an only child equates to loss of the parent's role as parent (Kander, 1990). Role or gender-identification may establish a particular bond between child and parent, making the loss of the child a central loss. The loss of an only son or daughter can also result in a particular sense of loss. Losing a child who is handicapped can leave the parent feeling relieved or ambivalent, which may exacerbate feelings of guilt. Twinship has particular dynamics and so has the grief experience as the parent has to adjust to having one child, with all the concomitant anxiety about the possibility of losing the surviving twin, at a time when it is perhaps expected that having a surviving child ought to provide a measure of solace. If the deceased child is an adult, the death severs a long-established relationship with many degrees of interconnectedness even though some



appropriate separateness had been achieved prior to the death as a result of the child's independence.

### **2.1.5.2 Circumstances surrounding the loss**

Some deaths are more 'appropriate' than others such as that of an elderly person whose death is expected. Worden (1988) suggests that accidental deaths may increase feelings of helplessness which expresses itself as anger and blame. Sudden deaths may be associated with greater difficulties as may deaths which occur at a removed locality. Calhoun and Tedeschi (2001) have found that bereaved parents had greater difficulties adjusting to the loss when the cause of death was suicide, when the death was unexpected and sudden and when there are no surviving children. Bailey, Kral and Dunham (1999) confirm that where the cause of death is suicide, the bereaved experience more frequent feelings of rejection, responsibility and more total grief reactions which they link to the increased levels of shame and perceived stigmatisation associated with such a mode of death. When the outcome of an event cannot be altered such as occurs with a death, control is out of reach. The survivor is then faced with altering the meaning of the situation and their emotional response to it (Moos, 1986).

Neugarten (1968) has proposed an interpretation in terms of a life events framework. According to this, it is important to understand how the sociohistorical context influences the timing of important life events. In terms of that, it would be easier to cope with an event if others in the cohort of the affected individual are experiencing similar events. Where events have strong correlation to age, the person is able to anticipate the development of coping strategies that may help to alleviate some of the stress they are likely to engender. Conversely, an idiosyncratic event has a low probability of occurring so there is little preparation for it psychologically. In this respect, it would be easier to cope with the loss of an elderly parent than of an offspring.

An AIDS-related illness as a cause of death, may not be idiosyncratic in terms of the sociohistorical context. However, the following factors tend to complicate the grief (Kelley, 1997):

- The experience of suffering a multiplicity of losses such as the deaths of others in the community, loss of health or employment and a subsequent lowering of economic status.
- The age of the deceased which in the case of AIDS sufferers tends to be young.
- Distressing symptoms such as pain, or disfigurement.
- Difficult treatments which cause the infected person to struggle or suffer.
- Social isolation resulting from a fear of contamination and the stigma attaching to the illness.

### **2.1.5.3 Personal factors**

The age and gender of the bereaved person can be significant. The impact of bereavement might be greater for older individuals who may be coping with age-related health and personal losses (Rando, 1986; Sanders, 1988) An inability to attribute meaning to life in general, is exacerbated, for some older parents, by the loss of a child, so that their ability to cope with the bereavement is lessened (Arbuckle & de Vries, 1995). Older parents may also have diminished resources as regards strength and options for reinvestment and nurturance following the death of their child. Moos (1986) notes that involvement in altruistic causes may be helpful in assisting recovery, but this may not be an option for the older bereaved parent. It would seem then that the bio-psychosocial situation of these parents might make the grief process more difficult and impede resolution and subsequent growth.

There is disagreement in the literature about whether mothers suffer more than fathers after the death of a child (Shapiro, 1994). It is believed that their more intimate emotional connection to the child makes mothers more vulnerable, as does the more central role that motherhood plays in the life of women as compared with the less central role of fatherhood in the life of men.

Zinner (2000) suggests that (especially American) men tend to be marginalised in grief and loss. The social constructionist view of grief posits that society has a 'template' for how grief should look, and hence how it ought to be expressed. The accepted 'look of grief' as portrayed in the media is characterised more by qualities

associated with femininity such as sighing, crying and slowness, rather than those associated with masculinity such as anger, irritability and impatience. Some of the 'masculine' or instrumental style characteristics, quoted by Zinner (2000), which are in opposition to the 'conventionally-accepted' or intuitive style of grieving are:

- A reluctance to confront the emotional tasks of grief.
- A reluctance to access social and professional support.
- Rejecting help as a show of strength.
- Lesser expectation of society of the need for social support.

Golden (in Zinner, 2000) notes that it took him many years to understand that conventional grief therapy is designed for women, partly because there are more female clients than male. Women do not necessarily feel their loss more painfully than men, but there is evidence that they are far more prepared to express it.

In research carried out by Riches and Dawson (1996), the willingness of mothers to talk about painful events and personal experiences contrasts with their husbands' greater reticence and more 'considered' accounts of events. For masculine-style grievers, the need to reject help in order to be seen as strong and as a survivor, fits with a society that values stoicism and strength in males. Moreover, by not displaying grief in the conventional manner, the male griever is less acknowledged by society as being a legitimate griever, something that Doka and Martin (2000) label a 'double-disenfranchisement.' Strategies employed by the male griever in coping with the emotional pain of loss, include:

- Shelving thoughts and feelings to meet work and personal obligations.
- Expressing grief externally by active means and by 'doing' rather than 'sharing'. An example of this would be to build something which is meaningful in the context of their relationship with the deceased.
- Indirect expression of feelings, perhaps using humour.
- Private ventilation of feelings in a journal or through music
- Retreating to a private space like working alone on a hobby.

Personality disorders also affect the course of the grief process, especially as regards the ability of the bereaved person to cope with the anxiety or stress of the bereavement. In this respect, those classified with borderline personality disorder or

narcissistic personality disorder, find it more difficult to cope with such a loss. This is also the case for persons who have a history of depressive illness (Worden, 1988). Recent research by Martin and Doka (2000) has found that the most predictive factors for positive bereavement outcome were positive self-esteem and personal competencies in managing the tasks of daily living.

Holmes and Rahe (1967) have hypothesised regarding the cumulative effect of losses and their 'Schedule of recent experience' is geared towards being able to calculate the effect of losses that follow each other within a short space of time. However, Worden (1988) comments that this has not been borne out in research, possibly because different events are understood differently by people.

Other personal factors which can affect the grief process include cognitive and emotional maturity, ego strength and self-confidence as well as the experience of coping in earlier crises. While resilience and self-confidence can positively affect the outcome of a stressful events, a sense of invulnerability may increase the difficulty if illusions are devastated by the enormity of the crisis. Philosophical or religious frameworks help to define the crisis as well as assist in their resolution (Moos, 1986).



#### **2.1.5.4 Coping skills**

What determines how any crisis can be coped with, is not simply the precipitating event and its nature, but also the coping style of the individual (Hafen et al., 1996). Moos (1986) suggests that various coping skills are used when dealing with the adaptive tasks necessary for managing a crisis. The choice of skills employed may vary according to the requirements of the situation, as not all are equally well suited. Three domains of coping skills are identified:

- appraisal-focused coping encompasses the process of appraisal to understand or modify the meaning of the situation. This requires logical analysis, mental preparation, cognitive redefinition, cognitive avoidance or denial.
- problem-focused coping deals with the tangible issues so as to create a better outcome. This entails seeking information and support, taking problem-solving action and identifying alternative rewards.

- emotion-focused coping aims to manage the feelings that a crisis sets off so as to maintain a balance in the emotional sphere. It requires affective regulation, emotional discharge and resigned acceptance.

The central question inherent in the salutogenic perspective Antonovsky (1979), is to establish what enables people to recover from stress or not to succumb to extreme strain. Antonovsky criticised the basic assumption of the biomedical model where disease is viewed as a deviation from health. According to this model, pathogenic conditions and agents must be identified, and the aim of therapeutic intervention is to eliminate them. The salutogenic approach endeavours to strengthen resources in order to make the organism more resilient and more able to resist weakening influences. Within this paradigm, health and illness are opposite ends of a continuum, so that even a high level of health contains a measure of ill-health, and vice versa.

While external events, such as the experience of trauma can be detrimental to health, different individuals respond differently to these events in terms of health and coping. A major role then, is played by the cognitive and affective-motivational outlook of the individual, as this determines the extent to which the individual is able to utilise available resources to maintain well-being. This outlook is termed the sense of coherence and it includes the sense of consistency, congruence and harmony. It encompasses a "feeling of confidence that one's internal and external environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected" (Antonovsky, 1979, p.10).

The three dimensions of experiencing the world as coherent and meaningful are:

- The sense of comprehensibility. This refers to a cognitive processing pattern and means that stimuli are experienced as ordered, consistent and structured, irrespective of whether they are familiar or not.

This dimension is formed through experiences of consistency in the life of the individual which reinforce the understanding that experiences can be classified and structured in an orderly fashion.

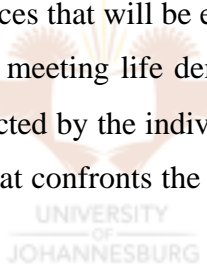
- The sense of manageability. This refers to a cognitive-emotional processing style and includes the individual's belief that difficulties can be solved as a result of using either one's own or other resources and competencies as required.

The sense of manageability develops through experiencing balanced strain, and avoiding both overload and underload.

- The sense of meaningfulness. This refers to the extent to which the individual experiences life as making sense when seen from an emotional point of view, such as whether tasks are viewed as challenges or are seen as burdens. This motivational component is considered the most significant of the three as it determines whether or not an experience will have a high sense of coherence.

The feeling of having influence on the outcome of events fosters a sense of meaningfulness (Antonovsky, 1979).

The sense of coherence is dynamic because it is affected by life experiences, and also influences the kind of life experiences that will be encountered. A well-defined sense of coherence enables flexibility in meeting life demands (as opposed to rigidity) so that the coping strategy that is selected by the individual will be the most appropriate one for dealing with the stressor that confronts the individual (Bengel, Strittmatter & Willmann, 1999).



The strength of the sense of coherence determines whether a stimulus is defined by the individual as a stressor or not. Once a stressor is detected it can be differentiated as either a favourable or an irrelevant one, which leads to a diminution of tension without the use of resources, or it can be defined as threatening. Even tension-engendering stressors will not be threatening if the individual's sense of coherence is strong because of their belief that the situation will resolve itself. However, where the sense of coherence is weak, individuals tend to react with diffuse emotions (such as rage) that are difficult to control. Their lack of confidence in their ability to resolve the situation tends to immobilise them (Bengel, Strittmatter & Willmann, 1999).

The variables that facilitate successful coping with tension are termed Generalised Resistance Resources (GRRs). These include individual factors such as intelligence,

social factors such as social support as well as cultural factors such as cultural stability. They can be effective in many different situations (Generalised) and function as potentialities which are activated during a state of tension. They increase resistance by helping the individual make sense of the stressors which assail him or her. This quality makes life experiences coherent and this forms the basis for the individual sense of coherence. As is the case for the health-illness dichotomy, it is possible to consider resistance resources and resistance deficits as poles on a continuum with the negative pole representing those experiences that weaken the sense of coherence, and the positive pole representing those experiences that strengthen the sense of coherence (Antonovsky, 1979).

While losing a child is always a significant stressor, the effect of the sense of coherence in managing the subjective experience of the bereaved individual is significant as it can provide buffers and mobilise resources, enabling the bereaved parent to make choices that promote health. The sense of coherence also acts as a filter in information processing, and thus plays a central role in the way the individual assigns meaning to the experience, which is a significant contributor to coping with an event of this magnitude.

### **2.1.6 Cultural and social aspects**

Not only does culture define patterns of kinship and relationship, but it also defines the quality and nature of relationships at many levels. For instance, the degree of attachment may be culturally determined so that in societies where there is little expectation for the survival of a child, attachment is limited until adolescence (Martin & Doka, 2000). Society also has norms regulating the expression of emotion and these define who may grieve, what one may grieve and how to express such grief. When the individual experiences grief which is beyond these socially accepted parameters, it is termed disenfranchised grief (Martin & Doka, 2000). Societal and cultural norms also divide tasks according to gender, and men in Western society have tended until recently to live life in the public sphere and women in the private sphere, so that the loss of a child may impact more severely on a woman.

Shapiro (1994) notes that since the publication of Becker's *Denial of Death* and *Death and Dying* by Kübler-Ross (1974), many people are cognisant with the stages

of grief. She also contends that where culture prizes personal mastery over adversity, the experience of loss is profoundly unwelcome as it exposes the vulnerability of the individual to the vagaries of fate. It is this that brings about a shattering of those assumptions regarding the sense of control that human beings have over living and dying. There is a sense of solidarity among those who share some of the devastation of the loss and of the changed view it gives of the world. Outside of this culture are those who fail to appreciate the enormity of their loss, or who deny its significance, or who expect them to return unchanged to the everyday routines of 'normal' living.

Others have described how the unwillingness of other people to confront the reality of death can create "a conspiracy of silence surrounding the death," (Yorkstone, 1981). After the death, families and friends will offer help to the bereaved in the form of comfort as well as practical assistance for the arrangements that need to be made such as funerals and legal procedures. However, for the bereaved person, the initial period is marked by a sense of numbness and shock, which only later gives way to intense grief, and this is the vulnerable time where support may be less available, leaving the bereaved at risk if unsupported (Yorkstone, 1981).

Kastenbam (in Martin & Doka, 2000), suggests that in cultures where the rate of infant and childhood mortality is high, attachments to offspring are limited by social norms and cultures. Today in Western cultures however, few have experienced the loss of a close family member and find it difficult to acknowledge the depth of pain that a bereaved person experiences. In 1900, one half of all parents would have experienced the death of a child but by 1976 only 6% would have done so. The socio-historical context of bereaved parents in Western society is such that a child's death is statistically less prevalent than in earlier historical periods (Farnsworth & Allen, 1996). As a result of this, the experience of the bereaved person is one of intense isolation. With these shifts in occurrence, the death of a child has come to be viewed as a devastating loss from which a parent may never fully recover, instead of a normal hazard of parenthood.

Lazare (in Worden, 1988) has highlighted the importance of the social setting as this is the context of the grief process. Three social conditions have been identified that may serve to complicate the grief reaction. Where the cause of death is seen as



socially unacceptable to the extent that it cannot be spoken of, it might result in a 'conspiracy of silence' that isolates the bereaved person who may be needing to talk about the event. A second factor that can complicate the grief process is a situation where the loss is socially negated, as could happen in the case of abortion, where others may not recognise the magnitude of the event for the person who has sustained the loss. Thirdly, a social support network is made up of people who knew the deceased and who can be supportive of one another. Social isolation through relocation, can result in an absence of the social support network and this increases the risk for a complicated grief process.

However, although social support is an important determinant of the grief process, it is only a moderate predictor of bereavement outcome (Martin & Doka, 2000). While the support that social networks can offer has a positive impact on the grief process, unrealistic expectations can diminish this benefit.

### **2.1.7 Anticipatory Grief**

In an expected death, anticipatory grief has an effect on the mourning process subsequent to the death of the child. The term anticipatory grief was conceived of by Lindemann (1944) who found that prior knowledge of the anticipated death can result in mourning prior to the actual death, rather than after it. Worden (1988) suggests that awareness of the impending demise facilitates an acceptance of it, even though this acceptance alternates with denial. Separation anxiety is also common and may be exacerbated by existential anxiety as identification with the dying person causes the soon-to-be-bereaved person to face the fact of their own mortality. The task of adjusting to living without the deceased is rehearsed during this period of anticipation.

While there is agreement that anticipatory grief does have an effect on the mourning process, there does not appear to be consensus as to whether the effects of anticipatory grief are beneficial or detrimental once the bereavement occurs. Walker, Pomeroy, McNeil and Franklin (1996) found that for caregivers the sense of commitment, loyalty and attachment which is developed during the process of caring for the sick individual, tended to increase the intensity of the post-death grief experience.

While some researchers have found that anticipatory grief can ease postdeath grief, others have found that it is unrelated to the postdeath grief process (Walker et al., 1996). It is possible that other factors account for these discrepant findings and according to Rando (1986), it would appear that there is optimal period for anticipatory grief of about six to 18 months (Walker et al, 1996). In the case of HIV/AIDS, the course of the illness can last for longer than this period so that some of the possible benefits of the anticipatory grief experience may be nullified.

### **2.1.8 Complicated mourning**

Since the distinction first made by Freud (1991) between mourning and melancholia, much of the literature has focused on attempting to differentiate between 'normal' and 'abnormal' grief which has been variously called pathological, unresolved, chronic or exaggerated grief. Worden (1988) suggests four categories of complicated grief. Prolonged grieving, without prospect of a satisfactory conclusion is chronic grief. Delayed, inhibited or suppressed grief may occur where a sufficiently significant grief response does not follow at the time of the loss. In this case a later loss may activate the grief of an earlier loss. According to Bowlby (1969), grief of this kind can be triggered by the attempt of the newly bereaved person to seek comfort from an earlier attachment figure, who may have died some time previously. As it is not possible to join with this figure the loss of that attachment is felt afresh.

Exaggerated grief is marked by excessive and disabling reaction to the death which manifests as a phobia centred around death, or irrational despair which persists for an extended period of time. Masked or repressed grief presents as a physical symptom or aberrant behaviour. In this case, the symptom or the behaviour can be symbolic of the grief reaction, which is suppressed (Worden, 1988).

According to Worden (1988) there are various factors which can precipitate complicated grief. The type of relationship that existed between the bereaved person and the deceased can be significant. Ambivalent, narcissistic or highly dependent relationships appear to be difficult to grieve. The circumstances surrounding the loss such as multiple losses, or an unconfirmed death are factors to be taken into consideration. The personality of the bereaved person and their specific history

especially as regards depressive history, are additional significant determinants. As grief is a social process occurring within the context of a social setting, social factors are also important determinants. Factors which could exacerbate the process include: a lack of social support; a loss that is negated from the perspective of the social setting; and finally a cause of death, such as suicide or AIDS, which may be considered socially unacceptable

Kalish (1981) agrees that the type of death has a bearing on how difficult it will be for the bereaved to resolve their grief. The following are examples of deaths that are more likely to be complicated:

- Unconfirmed death where no body has been found.
- Homicide.
- Death where the bereaved person feels a sense of responsibility for the death.
- Suicide or death due to self-neglect and carelessness.
- Untimely death, as in the case of young people, people just married, or people about to achieve something significant
- Death that required the bereaved person to care for the dying person in a manner that proved to be distressing.
- A drawn out dying process where the survivors become impatient for death to occur.

The last four factors enumerated above would tend to be implicated in the case of the death resulting from an AIDS-related illness.

### **2.1.9 Parental loss of a child**

Grief does not result equally in the case of all losses. Where the loss of a relationship leads to a grief reaction marked by intense and lasting distress as a result of the absence of the individual, such a relationship is termed a relationship of attachment (Weiss, 1988). In the case of such relationships, the distress (grief) cannot be diminished even if another individual takes the place of the deceased person within a relationship: another spouse or a child cannot replace the one that is lost. Such relationships are characterised as attachments as a result of their similarity to the relationship of the child in respect of the parents. The availability of the attachment figure fosters feelings of security which is verified through contact

(visual, tangible or auditory) with the attachment figure, or through the promise of future contact. Apart from the fact that such an attachment figure cannot be substituted, other common factors are that the attachment is not conditional upon the treatment of the individual by the attachment figure and that these attachments persist over time (Weiss, 1988).

According to Weiss (1988) conditions that threaten either the self or the continuation of the relationship will trigger the demonstration of attachment feelings and behaviours and if these are thwarted then separation distress will inevitably ensue as it is not a matter of volition. This state is characterised by a sense of anxiety, vigilance and searching for the attachment figure that is consuming for the bereaved person to the extent that it gives rise to sleep disturbances and an inability to focus on other concerns.

He has identified four relational bonds that fit these criteria and parental attachment to children is one such bond. Furthermore, the reaction of parents elicited in response to a threat to the well-being of their child is evidence supporting the argument that the emotional systems underlying the relational bond of a parent for a child is derived from their own attachment relationship in childhood. Significant others within the social milieu provide a context for a person to understand, define and validate feelings and experience and are important for one's definition of self. The loss of such a person therefore, can lead to a loss of the foundation for dealing with experience, as well as to a sense of uncertainty about one's sense of self.

Although loss of a child has been less researched than conjugal loss, some researchers believe it is perhaps the most difficult adult bereavement (Arnold & Gemma, 1994, Braun & Berg, 1994; Sanders, 1988; Singh & Raphael, 1981). Rando (1986) describes various idiosyncratic factors that can influence the grief experience. These include the nature of the relationship between parent and child prior to the death and the meaning that the child had for the parents; characteristics of the deceased child as well as characteristics of the bereaved parent such as coping behaviour, personality and socio-cultural background; characteristics of the death event, whether it was sudden or expected and the perception as to whether or not it

was inevitable; social factors such as the extent of social support available to the parents; physiological factors such as the health of the parents.

McIlwraith (1998) suggests that feelings of guilt are a significant component of the grief experience of bereaved parents. Feelings of having failed or having done something wrong can be overwhelming. Perhaps this is related to a belief that as the parents are responsible for having brought the child into the world, they should be able to ensure the survival of the child. Hence the inability to ensure the continuation of their child's life, however illogical, may result in feelings of failure as a parent and by extension, of feelings of failure as a person.

### **2.1.10 The effect on the family system**

Shapiro (1994) argues that grief for a the death of a family member is twofold: it is both a crisis of attachment and a crisis of identity impacting on the family's interactions and social roles which may need to be renegotiated. The first priority for the family is the necessity to re-establish the equilibrium necessary for allowing the family to continue functioning. This occurs at a time of intense emotionality for the family members. Paradoxically, while sharing one's grief experience would be important in order to allow family members to feel understood and to re-establish a coherent sense of the continuity of the family over time, members refrain from doing so fearing that this sharing might threaten the family's emotional stability.

Rando (1986) argues that the death of a child impacts on the marriage of the parents as it alters the dynamics of the marital relationship disrupting the habitual patterns of communicating and relating. Although the loss of the child initiates each parent into the grieving process, the individual experience of their grief can be as different for each parent as was their relationships with the child. At a time when each partner is in need of the support of their spouse, their spouse is equally in need of support.

The sexual relationship of a bereaved couple may be affected as a result of lack of desire or energy, adding to intimacy difficulties (Johnson, 1984). Some of the difficulties resulted from the meaning of intercourse as the means of having conceived their child or from the pleasuring of intercourse being inconsistent with the experience of grief and grieving (Hagemeister & Rosenblatt, 1997). It can also

highlight differences between partners as they differ in what the sexual relationship means to them, and what they need and want (Schwab, 1992). Some researchers have found an increased likelihood of divorce in couples subsequent to the loss of their child (Wortman & Silver, 1989), while others find the incidence is no greater than that in the general population (Rando, 1986).

The impact of the loss, also affects the homeostatic balance of the family as family members attempt to adapt to the new constellation. Each family member responds idiosyncratically and this can be a source of difficulty as each family member grieves within the context of the family (Rando, 1986). Although each member is affected individually and uniquely, the grief reaction of each individual is fashioned also by the needs and reactions of others, as well as by the availability of emotional resources which are strained at this time.

For the bereaved parent, the loss of a child, ushers in a period of crisis wherein the parent reviews his or her role as a parent. This radical life-review occurs in parallel with other family members who are themselves undergoing a process of similar magnitude so that the collective burden of the family to provide support to one another is significant at this time (Shapiro, 1994).

According to Shapiro (1994), losing a child initiates a transformative life-cycle transition. During this process the love-bond for the child that has died is not forsaken, but a new internalised relationship is forged which is both enduring and important to the remaining family members.

Shapiro (1994) argues that in the context of a systemic developmental framework, grief is considered a family developmental crisis that reshapes the future course of shared family development. The family needs to marshal all resources for this kind of crisis which touches on both attachment and identity in order to re-establish the necessary equilibrium for ongoing family development. Integration of the reality of the death continues throughout the family life cycle with each new developmental stage ushering in new opportunities for integration. In order to reintegrate the deceased into the family, it is necessary to develop an evolving spiritual and

psychologically supportive presence that goes forward with the family with the passage of time.

Gilbert (1996) takes a constructivist/interpretive view of grief within the meaning-making system of the family. Hence, grief results from the loss of meaning that resided within a significant relationship. The degree of grief felt is directly related to the importance of the lost relationship for the bereaved. The grief process then, can be construed as the reconstruction of a predictable and manageable new 'normal' world in which the bereaved person will be able to function. In addition, the sets of assumptions that the individual held prior to the loss need to be re-evaluated and reconstructed into a new assumptive world. This process entails the questioning of the assumptions which underly beliefs and behaviours, and this emotional upheaval impacts on interpersonal, relational and social systems.

Seen from the perspective of the individual in the family, Gilbert (1996) believes that family members construct a common reality for the family through the confirmation or otherwise of the beliefs of the family members. This reality is then accepted and acted upon unless contradictory evidence is produced to disconfirm such beliefs. This is a collaborative and ongoing process which occurs continuously in the life of the family, and at the time of the loss serves as a basis for interaction between family members. It is this also that makes it possible for family members to believe that they share a view of the situation, even though each member's subjective reality is individually determined. It appears that there is a strong desire for family members to share a particular view of their common loss, to the extent that it is hard for spouses to accept that their partner's style of grieving differs from their own.

In terms of the functioning of the family, once the nature of the loss has been recognised, the family needs to reorganise itself to function without the now-deceased member. Rituals can serve to facilitate the passing-down of a role from the deceased to a surviving family member. Eventually family members are able to transform the memory of the lost family member so as to continue with their lives and invest in the new family with a continuing sense of connection to the deceased (Gilbert,1996).

In a study of the narratives of bereaved parents, Rosenblatt (2000) has found that death rituals were prominent. Rituals which help to give meaning to the child's death include rituals of baptism, autopsy, police inquiry and organ donation. Funerary rituals include wakes, funerals, memorial services and burials, and these help to define the child, the death and changes in the parent-child relationship.

Both attachment theory and role developmental theory have attempted to find an explanation for the scale of the experience that parents undergo at the loss of a child (Rando 1986; Raphael, 1983; Weiss, 1988). The death of a child re-activates internalised aspects of the parent's own early relationships. In addition, the child represents, for the parent, an investment in the future so that the loss of a child can be equated to a loss of aspect of the parent herself or himself, almost like an amputation (Klass, 1988).

Bowen (1978) emphasises the importance of taking into account at least two generations of family history, because postponed mourning from an earlier loss impacts on the current loss. Important areas that need to be considered are the role the deceased played in the family, the emotional integration of the family and how that emotional integration is achieved. Worden (1988) suggests that the stress of losing a child impacts heavily on family equilibrium, as is evidenced by the number of marriages that end after such an event.

A further source of difficulty, for both the parents and family of the deceased child, can be the attitude of society to the loss of a child. The loss of a child is a stigmatising event to the extent that there is no word to describe the altered status of a bereaved parent which corresponds to words such as orphan, widow or widower (Hicks, 1995). Parkes (1972) notes that association with the bereaved can confer the taint of death so that expressions of sympathy and offers of help may be spurious. In his autobiographical account of the experience of loss, Lewis (1978, p.13) notes that as a result of awkwardness around the topic of death, people avoid the bereaved so that he suggest that "perhaps the bereaved ought to be isolated in special settlements like lepers."



Patterns of social relationships may change resulting in a sense of abandonment for the bereaved parents and family, at a time when the need for social support is great. Boston and Tresize (1988) suggest that others fear the bereaved person, and that once the socially recognised period of mourning, of perhaps six weeks, has passed there is considerable pressure exerted on the bereaved person to pretend to be well again. As a result the bereaved feel that their misery makes them socially unacceptable as their presence spoils the fun of others. The finding by Rando (1983) that the grief of bereaved parents worsened during the third year, highlights the gap between the social expectation and the experience of the bereaved, accounting to some degree for the sense of isolation. Calhoun and Tedeschi (2001) also found that a significant change in bereaved parents is not exhibited until at least two to five years following the death of their child.

According to Rando (1988) the quality of social experiences, as well as the interactional processes with the dying child, have an influence on the mourning process, and impact on the emotional and psychological processes of the bereaved parent. The acceptance by, and assistance from, of the parent's social support system is also an important factor, as are the funerary rituals utilised. (Rando, 1986). Research by Brotherson (2000) confirms that the circumstances surrounding the death of a child have a significant impact on the nature of the grief experience of the parents.

Marginalisation of the bereaved parent can occur when the bereaved parent serves as a reminder that, contrary to expectation, a child may predecease its parents. For the bereaved parent this marginalisation accentuates their feelings of guilt (Rando, 1986). Society may exhort the bereaved parent to 'be strong' or 'have courage', so that the bereaved parent may believe that expression of grief in a manner appropriate to the depth of feeling, is not socially acceptable.

## **2.2 Meaning-making**

### **2.2.1 Introduction**

Throughout history humankind has attempted to make sense of human existence. The tendency to attempt to create meaning is so central to humanity that, when

coupled with humanity's capacity for symbolisation, it appears to be inherent to the human condition. From an historic perspective, myth and the introduction of religious frameworks can be understood as formalised ideas regarding an attempt to find an understanding of the meaning of life. The power of such frameworks to provide meaning waned with the rise of empiricism. The meaning of life which had been so clear, became indistinct, producing an existential vacuum. The loss of these fundamental assumptions, which were the cornerstones of individual and societal behaviour, has prompted the search for meaning.

### **2.2.2 Reality and meaning**

The aim of the Cognitive Revolution was to bring a more interpretive approach to meaning-making (Bruner, 1990). The focus was on the attempt to, "discover and to describe formally the meanings that human beings created out of their encounters with the world, and then to propose hypotheses about what meaning-making processes were implicated. It focused upon the symbolic activities that human beings employed in making sense not only of their world, but of themselves" (p.2).

These symbolic activities are embedded in culture and language, so that their usage not only reflects something of the nature of the community, but is also a significant aspect of the way the individuals within that community construct their consciousness. Implied in this concept, therefore, is the conviction that in order to understand the individual, it is necessary to understand how the intentional states embedded in the symbolic system of the culture form the experiences and acts of the individual.

Crossley (2000b) asserts that the sensory and perceptual faculties of human beings do not serve merely as conduits enabling an experience of the world, but also act interpretatively to create meaning of events in terms of their interconnectedness. Accordingly, "it is in the connections or relationships among events that constitute their meanings" (Crossley, 2000b, p.11). Furthermore, cultural meaning systems, such as language, provide the context for the creation of meaning.

Berger and Luckmann (1967) argue that reality can be understood by individuals as their lived experience. Common sense can be understood as the knowledge of

routines and habitual behaviours that are acted out by individuals and which give them a sense of their objective reality. Experiences are interpreted in terms of this objective reality and become meaningful for the individual when they are perceived as making sense in terms of that objective reality. Events that cannot be explained and are outside of these bounds, however, negate the sense of an objective reality by virtue of invalidating the structure that has been put in place to justify such reality. In response to this kind of crisis, individuals have to reconstruct their reality so that it will be able to accommodate this new experience because it cannot fit into their previously-held understanding of the world.

According to Janoff-Bulman (1992) a belief system may be necessary in order for individuals to accommodate new information as it provides a framework into which it is possible to slot such information. Not being able to assimilate or adjust to the new situation results in a state of unresolved tension. Existential theorist Frankl (1964a) observed that the need for meaning is a fundamental human motivator and that there is no reason to go on living in a world in which there is no meaning. This may be one reason for the high rates of mortality and physical illness among the bereaved (Stroebe & Stroebe, 1992). Yalom and Lieberman (1991) and Jaffe (1985) concur that bereavement sets off existential concerns regarding meaning in life and its transience. Furthermore, Frankl (1964a) believes that the ability for people to survive is dependent on their ability to derive meaning and purpose for their suffering.

### **2.2.3 Meaning construction**

The assortment of life experiences is used by people to construct a coherent and unified life-story in a way that takes cognisance of the temporal aspect. In this way stories become a vehicle for people to make sense of their lives to tell others about themselves. By recounting these stories also to themselves, people are able to construct a sense of their identity (McAdams, Diamond, de St. Aubin & Mansfield, 1997). Life events are woven into an integrated life-story and meaning is ascribed to all events through the connotation they attach to past events or experiences and the anticipation of future ones. In this way the present event is embedded in both the past and the future (in Crossley, 2000a).

Creating a story through the integration of discrete and sequential experiences requires establishing connections between them and other past and future experiences so as to achieve ownership of the story and hence to take responsibility for one's life. This story creation is always current, rather than retrospective and there is a continuous process of editing experiences so as to render them comprehensible. Like a miner panning for golden fragments in the river to combine into ingots, the individual 'sifts out' the elements that create the story. From the vast array of continuously occurring events and experiences, which occur almost in disordered fashion over time, the person selects and omits certain of them so as to produce a story that can hold together.

Spence (1984), in differentiating between historical truth and narrative truth, suggests that rather than recovering the past, individuals create a new narrative that is close enough to reality in order to serve their purpose at that time. The narrator is at the centre of the narrative, and the object of the narrative is not its 'truth' but its ability to make meaning of the sense of self of the narrator within the narrative. Hence self is not a fixed entity but rather a continuously reconfigured amalgamation of that which has occurred and that which is yet to happen (Polkinghorne, 1988).

While the narratives that individuals construct are a reflection of the culture in which they are embedded, the narrative also provides for the renegotiation of meaning. (Bruner, 1990). Hence narrative becomes the vehicle for instituting associations between the ordinary and the exceptional by making the exceptional comprehensible. When events occur in accordance with that which is expected, then an individual needs no further explanation. However, departures from the expected course of events trigger off a search for the meaning of the event, in order to construct a reality that is able to contain such meanings.

The personal story of each individual is also important when seen from the perspective of salutogenesis, because it is only in the awareness of the circumstances of the individual's life that the resources that contribute to recovery can be found and fostered (Antonovsky, 1979). This process is particularly significant when considering the central role that the sense of meaningfulness plays within the sense

of coherence. Without the experience of meaningfulness, even life itself becomes a burden.

#### **2.2.4 Language and meaning**

The notion of 'mimesis' first expressed by Aristotle, was the capturing of 'life in action' (Bruner, 1990, p.46). Ricoeur (in Bruner, 1990) expanded on this notion of mimesis by noting how it is a metaphor for reality which is born out of reality but understood in a new way. The capacity of the individual to create symbolic structures is thus dependent on the mimetic function of interpretation.

Symbolic meaning itself depends on the capacity of the individual to use language so that a symbol can represent another reality. While these representations are malleable, they are 'fitted' into the individual's personal 'theory' of the world, and consequently their predisposition to construe the world in a particular way. Crossley (2000b) also emphasises the role of language as the vehicle for making the lived experience meaningful, and that "individuals understand themselves through the medium of language, through talking and writing, and it is through these processes that individuals are constantly engaged in the process of creating themselves" (p.10).

Segal (1999) has demonstrated the use of metaphor in psycho-therapy as an appropriate vehicle for providing symbolic meaning. In this sense, metaphor can be used to integrate the worlds of emotion, thoughts and beliefs. Furthermore, using metaphors provides an element of 'safety' where it comes to dealing with emotionally charged issues enabling the exploration of ideas which would otherwise be less accessible. In a sense it provides an entry point through which elements of the world of the unconscious can enter into the conscious.

Rosenblatt (2000) has observed that the narratives of bereaved parents include many metaphors. Metaphors for grief make it easier to talk about grief as an entity which has substance and impact. Some of the metaphors used to explain the grief process are: 'draining', 'emptiness and holes' and 'part of me died'. Talk about dying is often also expressed in metaphor and death can be seen as a battle, struggle or resistance against something harmful. 'Passing away', 'loss', 'letting [the child] go', 'could not get [the child] back' are metaphors used to describe dying (p.59). However, as he

points out, while the metaphors used reveal something of the experience, they also obscure something else of the experience. For instance, using the metaphor of emptiness and holes obscures how much the child and the child's death fills the parent to overflowing with suffering.

Husserl (in Mohanty, 1969) contends that while it is possible to find the meaning-function in the absence of speech elements, the converse is not possible. Because the essence of a communication exists in the meaning, it is possible that a representation of reality is as valid for fulfilling the meaning function as the existence of an actual reality. Husserl argues that just as many meanings can be attributed to the same object denoted by a word, so one perceived thing may be related to many things as they are perceived. These are termed perceptual noemata. It is immaterial whether these noemata are real or unreal, physical or mental. In other words, there is a concern with the analysis of the individual's experience of meaningfully using a specific expression. However, the meaning-intending act may not be obvious and may only become so subsequently in the act of reflection. Understanding in this sense, then, is the grasping of meaning (Warnock, 1970).

According to Kierkegaard (in Palmer, 1996) indirect communication and metaphor are unbalancing in that they destabilise the smug complacency that stands between the individual and the truth. This kind of communication leads back into the self and necessarily reveals something of the subjective world of the one using the communication. There are no objective criteria for establishing subjective truth, and yet subjective truth is essentially related to the existence of the individual, the values and the foundation of such values of the individual. Hence values and morals, be they religious or aesthetic, originate from the sense of self of the individual.

### **2.2.5 Suffering and meaning**

Frankl (1964b) has demonstrated the power of the individual's perceived meaning of an event to allay pain and suffering, even where the situation includes experiences which are horrifying and degrading. He has classified values into three groups in terms of creative, experiential and attitudinal values. This reflects the way in which individuals are able to find meaning in life as values must be lived in a manner which makes sense for the individual.

Frankl (1964a) contends that the meaning of existence is not invented by the individual, but rather discovered. In this journey of discovery, values act as a pull, which emphasises the role freedom as a central dimension of the process. The individual is thus not obliged to fulfil or reject the potential of meaning. As the search for meaning yields answers that are idiosyncratic and specific, what is important is the particular meaning at an identifiable moment in the life of the individual.

It is possible that, as Frankl (1964a) reminds us, the fact that the question is asked at all, in the search for meaning, is more significant than the content of the question that is posed, because it demonstrates clearly the capacity of the individual for assuming responsibility for his or her own life. The consequence for such assumption of responsibility is for the individual to confront the finiteness of life and self.

Frankl (1964a) sees love as one of the ways through which meaning in life can be found and suffering is another. While suffering cannot be sought, once it occurs it opens the door to understanding the transitory nature of human existence. He contends that being brought face-to-face with an immutable reality motivates the individual to seek for life's meaning with transformed resolve. He states that "suffering ceases to be suffering ... at the moment it finds a meaning". (Frankl, 1964a, p.115). Self-transcendence is seen as a necessary adjunct to this process, making the spiritual dimension central to finding meaning in life.

It is possible then to find meaning in life by what a person gives the world in terms of his or her creations; by what the individual takes from the world as regards experiences and encounters, and the position that the individual decides to take in the face of an inexorable event. It is the human capacity to form and re-form oneself that enables the person to transform suffering from pain to meaning.

While death can be seen as an event that takes meaning away from life, Frankl (1964a) emphasises that the only potentialities in life are in fact the transitory aspects of life. As soon as they occur then they become part of the past where they are not lost but can be given meaning. In this way the transient aspect of life does

not make it meaningless but rather presents a selection of choices or possibilities where past deeds, joys and suffering can be salvaged or redeemed through memory.

As pointed out by Havenga Coetzer (1997) the spiritual sphere is central to understanding Frankl's concept of the will to meaning as faith can be understood as an "unconditional trust in ultimate meaning" (Frankl, 1964a, p.156). The term is not used in a voluntaristic sense to indicate a need for meaning which must be 'satisfied', but rather something that is discovered and not created by the individual. Meaning then is a final explanation which is external to the individual rather than internal and that "the meaning which a person has to fulfill is something beyond himself, it is never just himself" (Frankl, 1967, p.11). Meaning then, has the capacity to draw the individual towards a concern for life that is directed towards the future, so that the nature of meaning is inspirational (Fabry, 1967).

Gergen (1982) suggests that in the process of interpretation of experience, the individual is reflexive in that his or her understanding of the past can be altered in view of present experience, and the present altered in terms of the past. In this sense the past is fluid and so presumably then, is the future. Moreover, the individual has the capacity to imagine alternative ways of being or behaving. Through these twin processes the individual is able to re-evaluate and reformulate what is prescribed by the culture.

Rowe (1991) claims that in constructing an inner understanding of the world it is necessary to deal with the issues of life and death, the purpose of life and the supposed existence and nature of God. Maintaining the idea of the continuity of existence after death is made possible by a symbolic extension of life into an after-life. In a sense, what makes this possible is the metamorphosis of the fear of death into hope for continued existence. It is by this transformation that death can cease to be a hard, unbearable fact and become supportable and comprehensible instead.

In an observation arising from clinical experience, Klass (1988) notes that although the symptomatic descriptions which are common currency were accurate representations of the bereavement experience, they did not help to explain the long term changes to the self that were observed. Moreover, the models that were



available did not assist in understanding the intricate workings of the grief resolution within the social-support network and the complex life history of the individual. Equally significantly, the way that the individual integrates the multiplicity of their symbol systems into their social environment was not adequately explained. It seems therefore that models which do not contain these elements are not able to wholly reflect the totality of the grief experience and this further highlights the importance of incorporating the central role of meaning-making into any theory or model of bereavement.

Davis and Nolen-Hoeksema (2001) conjecture that the reason people seek meaning in loss arises from an inability to acknowledge the inevitability of death, and the possibility that it may occur at any time within the life-span. However, this does not imply finding a reason or causal attribution for the death. Rather it appears that the search is to find a transcendent meaning in the loss so as to make sense of it. Normative life events such as an age-appropriate death, and having spiritual beliefs are two factors which tend to facilitate making sense of the loss for survivors of a loss. However, although not all people express a need for meaning, an inability to find meaning, when it is sought, can result in despair.

According to Janoff-Bulman (1992), core beliefs are constructed over years of experience and these guide an understanding of the world. These abstract beliefs are about the self, the external world and the relationship between them, and form the core of an assumptive inner world. The core belief in respect of the world is that it is benevolent, and that there is a preponderance of positive outcomes over negative outcomes. The core belief in respect of the world as meaningful, means that there is a relationship between the individual and what happens to the individual. Self-worth is based on self-evaluation and generally there is a belief in the self as being good, moral and capable, so that the self is worthy. In addition to these assumptions, there is also a belief in personal invulnerability.

What makes an event traumatic is its ability to challenge these fundamental assumptions and indeed to shatter them. This disintegration of the inner world requires a creative reformulation in terms of a survivor perspective whereby the traumatic experience is re-interpreted and re-evaluated with the focus on the benefits

that have accrued from the experience. Successful re-formulation is characterised by an emphasis of benevolence over malevolence, meaningfulness over lack of meaning and self-worth over self-abasement. Janoff-Bulman (1992) suggests that one possible positive interpretation of a traumatic event for an individual is the sense of appreciation for life and self and an awareness of strength and the ability to survive. Another is turning the experience into a motivation for altruism.

Tedeschi and Calhoun (1995) agree that an increased sense of the ability to survive and sense-reliance can emerge as positive outcomes after trauma. Other positive outcomes can include changes in interpersonal relationships such as greater emotional expressiveness and a greater willingness to accept help and social support. Increased compassion, sensitivity to the needs of others and the ability to support others have also been cited in this respect. In the sphere of a changed life philosophy, a positive outcome is a greater awareness of the value of life, time and relationships. The degree of introspection may also foster a new life philosophy or spur the individual with renewed vigour in a spiritual direction.

### **2.2.6 Meaning-making and HIV/AIDS**

Crossley (2000a, p.519) posits that a life-threatening illness such as HIV/AIDS is a 'biographical disruption' that threatens the most basic existential assumptions that people have of themselves and their world. This challenges the concepts that the individual holds of the self, body, the world and the likelihood of a future existence. There is an enormous disruption in the sense of lived time, as opposed to time left to live, that results from the deconstruction of that which was previously taken for granted. In spite of this, most of the research has focused on the physical burdens of disease on the sufferer and caregiver and of the psychological aspects of stress that it entails (Carlisle, 2000).

Receiving a diagnosis of a life-limiting illness for the persons diagnosed, and those close to them, means that normal life ends and another takes its place where the planning for living is replaced by planning for dying. "Hence, an HIV-positive diagnosis has the capacity to fundamentally disturb one of the central characteristics definitive of the contemporary human being's existence; the fact that s/he lives in and for the future" (Crossley, 2000b, p.36). Accepting AIDS as a terminal illness while

maintaining a hope for a cure can be a major challenge in finding meaning for both the sufferer and their parents (Barroso & Powell-Cope, 2000). Perhaps the most difficult aspect for the parents of a child with HIV is the sense of not knowing how long their child will survive, and this relates to Frankl's observation that not knowing the length of the term of their imprisonment was the most depressing factor for a prisoner, reducing life to a provisional existence (Frankl, 1964a).

The long asymptomatic phase and the high degree of certainty of an AIDS diagnosis can give rise to an anticipatory grieving process in the person diagnosed as being HIV-positive. Finding meaning by accepting the presence of the virus was one specific active existential strategy. The desire to work in the HIV field as a professional caregiver or volunteer is another strategy that helps caregivers find meaning (Crossley, 2000a).

Wheeler (2001) concurs that the great majority of the bereaved parents in her study could identify meanings in their lives resulting from the bereavement. The most common areas of meaning-making or meaning acquisition were in terms of contact with people and helping others. Some of the positive changes arising from finding meaning in values and beliefs were valuing life, accepting that which cannot be changed, caring more about people, valuing the spiritual above the materialistic, and finding new religious-spiritual beliefs. Some bereaved parents found meaning from personal growth, such as feeling better about oneself, becoming a better person, and pursuing further education.

Many caregivers felt that they did not survive the experience of caring for a loved one who was terminally ill with AIDS as the persons that they had been before the advent of the illness. However, surviving the experience appears to confer a sense of success that gives new meaning to life in spite of the death (Carlisle, 2000). While for some sufferers and caregivers the experience was marked by crisis, such as attempted suicide, Carlisle (2000) notes that many sufferers believe that HIV and AIDS had brought a positive and permanent contribution to their personal lives through initiating a reappraisal of their feelings and the ways in which they acknowledged and expressed them, both to self and to others. While it may not remove the pain of the experience, the ability to engage in a restructuring of life

beliefs in the face of a challenging reality can reduce stress for caregivers. Hence, the finding of meaning can be a powerful way to redress the balance of the costs of caregiving with personal rewards (Carlisle, 2000).

For some parents, learning of the diagnosis leads to a knowledge, or exposure, of the lifestyle of their child, which may be especially intolerable to them (Kander, 1990). This is exacerbated where the child has contracted the illness as a result of homosexual contact, drug abuse or prostitution, as there may be exposure to moral condemnation by society, church and even the media. Moffatt (1986) describes the experience of shame as a "What-will people-think? syndrome" so that the climate of understanding and support that the mourner seeks during their grief process may be denied to them, even to the extent that mourners may themselves be reluctant to ask for the support of others.

Barroso and Powell-Cope (2000) have found that for some people the diagnosis of HIV or AIDS leads to a dissolution of the social networks that were previously supportive. For some people, such a diagnosis also leads to a severing of family ties. Families may not overtly reject the person living with HIV; however, keeping the diagnosis secret or adopting extreme measures to avoid contagion may lead to a reinforced sense of stigma because such covert behaviour could be interpreted as a subtle form of backing away (Barroso & Powell-Cope, 2000). For others, however, news of an HIV diagnosis could also bring families closer together or end previous conflict as a result of the process of evaluation, or 'value-ation' (Janoff-Bulman & Frantz, 1997, p.98) and the subsequent re-ordering of life priorities.

A basis for the sense of shame that can be experienced can be found in the Just World theory (Lerner, 1980) which suggests that people believe that they get what they deserve and deserve what they get. 'Common wisdom' also supports this view and sayings such as 'what goes round, comes round' tend to support this world-view. Seen from this point of view, it would seem that if a person is good, or leads a moral life, they should be spared misfortune. By contrast, misfortune would tend to happen to people who are not good, perhaps as a kind of punitive justice. In essence then, the question with regards to HIV/AIDS becomes more about why it occurs to specific people than why it occurs at all.

### **2.2.7 Meaning-making and parental bereavement**

Braun and Berg (1994) suggest that it is part of the natural order of life that parents should pre-decease their children. A natural corollary to this is the common sense belief or 'knowledge' that children do not die. The death of a child challenges this assumptive world order, and the world now appears to be out of control, unjust and unfair. Hence the death of a child threatens the very meaning structures associated with being a parent. In order to make sense of the occurrence, the world view needs to be changed so as to accommodate the new reality which can incorporate knowledge both of the child's death and of the continuity of life.

The current generation is the first one to be 'death-free' in the sense of a lack of direct contact with natural human death (Corr, 1979). This serves to distance human beings from their involvement in the community of living creatures, all of whom are destined to die. Hence the opportunities for reflecting on the meaning of death in order to understand something about one's own mortality are limited. As mortal beings, humans cannot be impartial observers in respect to confrontation with death, and the knowledge of death rouses many deep-seated emotions and fears in the survivors.



In his study of Western attitudes to death from the Middle Ages to the present, Ariès (in Corr, 1979, p.28) observed that between the twelfth and fifteenth centuries, "death became the occasion when man was most able to reach an awareness of himself." However, by the mid-nineteenth and twentieth centuries a feeling of distaste had developed regarding death, with a sense of it as shameful. Gorer (in Corr, 1979), has argued that in Western societies there has been a shift in prudery where, in contrast with earlier times, copulation has ceased to be an 'unmentionable' topic but death has become the ultimate obscenity instead. As a result, the image of death is almost erased subconsciously from the lived experience of people. In this sense it is imbued with a feeling of unreality and death is perceived to happen to others, to the sick or to the elderly.

Confronting the harsh reality of a disturbing death, such as loss of offspring, violates an implicit sense of the continuity of life. Language patterns too, reflect this

understanding so that there are many euphemisms in common parlance for referring to death and one of the reasons for using such words is the fear that to talk of death, although even to use the words, would be tantamount to courting death (Boston & Tresize, 1988). Capps and Bonanno (2000) have also emphasised the role of language especially in the way a narrative is grammatically constructed. Grammar can construct a particular view of the narrator in relation to it and reveal perspectives that might not be fully accessible to narrators themselves.

The feeling of intense anxiety or dread which is part of the experience of disintegration when faced with a seriously traumatizing event such as bereavement or a life-threatening illness was termed 'angst' by the Existential philosopher Heidegger (1962). If meaning for individuals exists in the connections and relationships, then the loss of a significant 'element' in this chain causes the whole complex configuration to fragment. In this respect, existential crises produce a sense of groundlessness as the person suffering a loss finds that nothing makes sense any more, rather like the vertigo experienced when faced with an abyss (Crossley, 2000b).

All facets of human functioning including the physiological, psychological and the social aspects are affected by the impact of a significant loss such as the loss of a child, as this kind of loss is frequently of a traumatic nature. It shatters the bereaved person's sense of being able to manage their emotions and relate to others, as well as shattering their world-view, which is their customary pattern of understanding their world. The sense of safety or trust in the world is dramatically affected as most people assume that their own death will precede that of their child (Janoff-Bulman, 1985; 1992).

The search for meaning is a way for bereaved individuals to try to integrate the death into their lives by constructing an understanding of the events surrounding the death. Understanding helps to restore a sense of being in control, rather than being powerless and helpless, even if this means resorting to self-blame (Shapiro, 1994).

Davis and Nolen-Hoeksema (2001) have found that people coping with loss tend not to be satisfied with a causal understanding of the death but seek a deeper,

philosophical meaning for their loss. While causal attributions such as the explanation that a physician can provide, can be an aid in the search for meaning, finding such an explanation rarely provides the reason that the bereaved person seeks.

Boston and Tresize (1988) have found that each individual tends to have vastly different meanings regarding death. Depending on one's belief it can be construed as a beginning, a transition or an end. Where there is a belief in an eternal existence, death becomes the doorway for re-unification with the beloved child who has died, and so death appears to contain all life's meaning. On the opposite end of the continuum, others attempt to describe death as nothingness, seeing it as an ordinary and insignificant event. Between these two extremes, bereaved persons must craft their own personal meaning of death. In the absence of a predominant religious belief, people draw on many traditions and religions to construct their own understanding of the meaning of the death.

Rando (1986) believes that the child is an extension of the parents psychologically, and the loss of the child leads to a sense of loss of part of themselves, sparking an existential crisis, so that the process of grieving becomes a means to re-create their sense of meaning of self. Brotherson (2000) too has found that parents struggle with a sense of parental identity after their loss of a child.

When a child dies, idealistic assumptions about motherhood may rapidly turn to self-blame and feelings of failure. Mothers, under these circumstances, are likely to feel marginalised by failing to live up to the benchmark family ideal where they are principally responsible for child outcomes (Farnsworth & Allen, 1996). The child embodies, for the parents, possible immortality and continuity of life beyond their own life-span, so that the loss of a child disrupts the sense of an orderly universe where the oldest die first (Rando, 1986).

Davis, Wortman, Lehman and Silver (2000) argue that a significant proportion of well-adjusted bereaved individuals do not search for meaning after a significant loss. However, the Leiden Bereavement Study (Cleiren, 1991) has found that the bereaved group most likely to be concerned with issues of meaning is that of parents who lose

a child. In addition, bereaved mothers appear to experience greater levels of guilt and anger as well as greater social isolation. Those parents who lose an only child suffer more than those who have surviving children.

In contrast to Rubin (1981), who argues that the goal of the bereavement process is the restoration of pre-loss levels of functioning, or Worden (1988) who sees it as 'working through' the grief, phenomenological theory suggests that there cannot be a return to a pre-traumatic state (Golsworthy & Coyle, 1999). This is supported by findings that bereavement and other threatening events can be catalysts for substantive changes within the individual. In this regard the goal of the bereavement process could be the creation of a new representation of the individual's reality.

Research by Braun and Berg (1994) has focused on the process of meaning reconstruction employed by bereaved parents. Where the explanation of the death cannot be made to fit the assumptive world-view, there is an extreme disorientation or shattering of previously-held beliefs, assumptions, values and norms. At its most extreme, such a degree of disorientation is incompatible with continued existence, so that the bereaved parent begins the process of adjustment to the prior meaning structure in order to restore a sense of meaning and purpose in life that is compatible with its continuation. Themes which were identified as properties of the meaning structure of parents prior to the death of the child that cannot account for the death, are:

- Centrality of the child's life in the parent's sense of meaning and purpose in life. This also refers to the way in which the child's life was central to the parent's experience of self and their vision of the future.
- Nature of life beliefs that include a sense of the goodness and justness of life, and include beliefs about immunity to tragedy.
- Personal control refers to the sense of being able to influence the outcome of events in their lives.
- External control refers to the belief about the existence of an external control such as God, and the power that is attributed to such a being.
- A belief in the existence of order in the world and that there are reasons for what happens.



An additional possible belief that is not able to account for a child's death, is where there is a belief that existence ceases at death, because this signifies that a premature death nullifies the ability to make meaning of life.

Braun and Berg (1994) suggest also that social factors contribute to the development of these meaning structures that are incompatible with the death of a child. Planned parenthood does not include a plan of losing the child. It also means that a parent has fewer children, in whom there is much personal and emotional investment. Also beliefs that life should be good, and that people are themselves responsible for outcomes. In addition the general denial of death of Western society where death only occurs to the elderly (after removal to a hospital, an old age or nursing home), makes the death of a child seem incomprehensible.

Where meaning structures fail to account for the child's death and the discontinuity it represents in the life of the bereaved person, there is a severe sense of disorientation. This sense of disorientation is characterised by feelings of being disconnected from the world, of a fragile life with consequent fear and distrust. Loss of hope for the future, a sense of powerlessness, loss of personal control and loss of purpose in living also contribute to the sense of disorientation. It is clear then, that the extent of discontinuity is what differentiates the loss of a child from other losses, as an entire collection of assumptions about life is undermined, and this strikes the parent at the level on which their whole existence is based.

The findings of Brotherson (2000) about parental behaviour in relation to parental identity suggest that connecting with and remembering the child in diverse ways are fundamental aspects of parental behaviour after a child's death. Possessions including clothing, photographs, letters and mementoes relating to the dead child may take on particular significance. According to Rosenblatt (1990) this is because the meaning inherent in them can assist in the definition of the relationship to the deceased.

The Two-Track Model of bereavement (Rubin, 1981) Track I comprises the overt symptomatology of the individual's biopsychosocial function of the bereaved person, and Track II comprises the more covert aspect of the bereaved person's continued

relationship with the deceased. In a later study, Rubin (1999) has found that whereas functioning for bereaved mothers on the basis of Track I improved as a result of more time having passed since the death, there was no difference between the two groups regarding their concern for the deceased (Track II). He notes that it is difficult to capture the essence of their experience in statistical findings, and highlights the importance of considering both Tracks because death does not necessarily bring to finality the bereaved person's attachment bond for the deceased.

Stroebe et al. (1994) also offer a dual process model where it is suggested that although bereaved people often attempt to make meaning of their experience, they also struggle to restore the lost order, using avoidance to cope with painful feelings. While traditional models view resolution of the grief as the ultimate goal, Stroebe et al. (1994) rather examine the different approaches used by bereaved parents to reconstruct their worlds to reflect a new and different view and how these efforts occur simultaneously with attempts to achieve some sense of resolution of the loss.

Neimeyer (2000) makes a cogent point that the focus of the meaning-making process tends to shift over time. The course of the life-story of the bereaved person is changed as a result of the death and there is an attempt to find new meaning for both the bereaved as well as some meaning in the death. The construction and integration of meaning occurs within a personal as well as social and cultural context and is particular to that individual, his or her history and the relationship that existed between him or her and the deceased. Although the social milieu also provides an audience for those new meanings to be tried out, the process of meaning-making is nonetheless highly personal and idiosyncratic. In contrast to Frankl's (1964a) belief that meaning must be discovered, there is no global 'meaning' that the bereaved person must find, but rather a process of creating or constructing a significant new understanding.

The purpose of these new understandings, and the narratives employed, is to facilitate the process of healing and reconstruction. As such, these narratives provide an entry point into the subjective reality of the person who creates them and can become powerful vehicles for clinical intervention (Neimeyer, 2001). Capps and Bonanno (2000) also see narrative as a pervasive and powerful tool for

reconstructing personal experience, and thus contend that a narrative approach is warranted given the tendency for bereaved persons to repeatedly revisit this event over the course of their lives.

Rando (1986) has found that losses may accumulate in the wake of bereavement, each one compounding the other, making the bereavement process more difficult. In the case of a parent whose child has died as a result of an AIDS-related illness, it would seem from the above discussion that there are various factors that might increase the need for finding meaning. Where a parent knows their child is suffering from a life-limiting illness, there is a face-to-face confrontation with death, pain and loss. The sense of repugnance both for the way the illness is transmitted as well as for the physical ravages of the illness can also complicate the grief process and in this way the AIDS-sufferer becomes a metaphor for these fears about disease and death. It is possible then that the search for meaning that is experienced by these parents is more significant than it would be if the terminal illness were non-stigmatised.

The idea that it is possible to experience growth after a devastating loss is not new. In 'The Prophet' Gibran (1973) asks, "Shall it be said that my eve was in truth my dawn?". Research by Moos (1986) has indicated that bereaved parents quoted positive outcome categories more frequently than negative ones. Positive outcome categories included statements such as being more grateful, compassionate, appreciative, serious about life, aware of the importance of loved ones, aware of the fragility of life and having a greater understanding of life and death. Negative responses included not being able to forget the loss, recover, or resolve the loss.

While Moos cautions that the self-selection aspect of the sample could mean that it may not be possible to generalise from the results, it is interesting to note that many of the parents indicated that they had found some meaning and grown since the death of their children. The existence of support groups such as The Compassionate Friends and Mothers Against Drunken Drivers among others, indicates the attempt by bereaved parents to channel the pain and rage of the loss into meaning endeavours. It is also possible that through this involvement the search for meaning can affect the outcome of the grief process positively.

Ramsey and Blieszner (2000), also emphasise the communal aspect of the search for meaning and that it is more than a solitary activity. Groups are also mentioned as a way for people who have shared similar experiences to make meaning of an event and build the resilience necessary for transcending suffering.

Tatelbaum (1983) has found that using affirmations for personal growth can provide the beginning for changes. Previewing possibilities enables the bereaved parents to imagine desired opportunities as a first step to transformation. Loss can launch the bereaved person into a new life in which making grief meaningful can act as an antidote to despair and suffering. It also becomes a springboard to personal growth and achievement (Calhoun & Tedeschi, 1990). Many bereaved parents go on from grief to become counsellors or healers for the suffering of others. They are then able to enhance their own lives through the compassionate helping of others.

Shanefield, Benjamin and Swain (1984) found that over half of bereaved parents in their study reported having experienced personal growth, becoming more emotionally expressive and more productive and were able to talk about sensitive emotional issues. There was also a commitment to living life more fully and meaningfully. Other studies have shown that bereavement may be associated with personal growth (Edmonds & Hooker, 1992). Kessler, (1987), Schwartzberg and Janoff-Bulman (1991) and Ulmer, Range and Smith (1991) have found that participants in their studies believe that their grief has led to a deeper appreciation of life and their surviving loved ones.

Creativity is used by some bereaved parents as survivors of trauma, to forge a new sense of reality and to rework the symbols and images of the trauma through working with others. There is also a transformation that occurs in the values, goals and assumptions that are held about the nature of the world and of the self (Baures, 1996).

Tedeschi and Calhoun (1995) found that areas of growth after traumatic loss included growth in character and an enhanced capability of being able to survive, strengthened relationships and an increased sense of connectedness, characterised by

a greater capacity for compassion. Other perceived areas of growth are a changed philosophy in life with a greater appreciation for life, and new understanding of spiritual beliefs. Davis and Nolen-Hoeksema (2001) however, differentiate the meaning-making process from that of finding benefit from the loss, as irrespective of the ability to make sense of the loss, people may be able to report some benefit to have accrued from the loss, which facilitates emotional adjustment over time.

Parental meaning-making is evident in much of the narrative presented by bereaved parents (Rosenblatt, 2000). This includes attempts to understand reality which becomes necessary where the child predeceases its parents because this is seen as an unnatural event which shakes the orderliness of life and hence is meaningfulness.

An accounting for the multiplicity of losses encompassed in the loss of a child can also serve as a foundation for meaning-making by defining what must be given meaning to. Loss of an imagined or envisioned future is an example of this (Rando, 1986).

Some parents seek comfort in recounting or enumerating how things could have been worse, or how the child is now free of a worse fate such as prolonged suffering. Searching for positive meanings is part of a process of reinvestment in life, not through negating the enormity of the loss, but by finding something in it that was not negative. Allied to this, is identifying the good that has come from the death, which is a legacy of their child (Rosenblatt, 2000).

### **2.2.8 Religion and spirituality**

While religion can be defined as a particular socially organised system of faith and worship based on human recognition of superhuman power, spirituality can be defined as the human propensity to find meaning in life through self-transcendence. In support of these concepts is the observation that spirituality often becomes particularly salient as people age and move closer to death (Golsworthy & Coyle, 1999). Yalom (1980) differentiates between secular and cosmic meaning. Secular meaning refers to meaning resulting from the belief that life is purposeful. Cosmic meaning refers to the belief in an overall order of life and sense of coherence about life events which may express itself as a belief in a higher power such as God.

In this regard, Corr (1979) argues that religion can be understood as an attempt by society and the individual to deny the reality of death or to somehow 'manage' it. Thus in many religions death is perceived as merely a stop on the way of an eternal existence which may variously incorporate doctrines of immortality, resurrection or reincarnation. However, faced with such a devastating confirmation that death involves the cessation of life, the bereaved person might be left to ruminate how even if the deceased is continuing to exist, they are no longer available in this current existence. Hence, Balk (1999) contends that some bereavements present a life crisis that force the bereaved person to review the meaning of life and one's place in the universe, and in so doing, provide the medium for spiritual change.

Crisis provokes questioning about the meaning of existence which can lead to a conversion of belief. Shanefield, Benjamin and Swain (1984) found that almost two-thirds of participants in their study experienced an increased sense of spirituality. As Kushner (1981) points out, questioning of faith is not restricted to those of lesser faith, and a repudiation of religion is as valid an outcome of the process as is the embracing of religion.

Research by Davis and Nolen-Hoeksema (2001) appears to indicate that having religious or spiritual beliefs appears to facilitate the process of meaning-making after loss. This is possibly a result of the fact that having a pre-existing world-view makes it easier to make sense of the loss, sooner rather than later in the process. The Stanford Bereavement Project (Davis & Nolen-Hoeksema, 2001) found that people who are unable to make sense of their loss within 6 months of the loss, appear to be unable to make sense of it later. However, finding meaning early does not put an end to the process of searching for meaning and this searching persists.

Watson (1986) contends that people who suffer behave as though there is meaning in suffering, and that this is evidenced by their quest for answers in posing questions. The meaning sought in asking questions is whether any good can come of the suffering, and whether there is any meaning inherent in the suffering. The framework for establishing meaning comes from the world-view of the individual, which fits on a continuum of epistemologies ranging from the secular/scientific

worldview to the sacred/religious worldview. In the former, the cosmos is seen as autonomous from supernatural forces, while in the latter, the cosmos is wholly dependent upon them. The former is an evolutionary model and emphasises the survival of the fittest and extinction of the maladaptive, while the latter describes existence in creationist terms of divine salvation. There is a tension between these antithetical worldviews that the individual needs to resolve so that science can admit a purpose to life beyond the observable limits of physics and religion can admit the possibility of organic etiology for illness and death. Archetypes for the meaning of suffering are naturalism (where death is seen as a part of human destiny), altruism (a belief that others may benefit as a result of the loss), correction (the loss as punishment) and affirmation (loss as the way to spiritual growth).

Golsworthy and Coyle (1999) concur that human beings create a structure of meaning that gives a sense of order and purpose to their existence and to death through religious and spiritual beliefs. However, it is important to also take into account the complexity of the phenomenon, such as the interactions between an individual's belief system and his or her response to loss. Hope appears to be a significant component of religion that imbues a sense of purpose to the loss, and for many bereaved people, meeting the deceased again in the next world is a significant aspect of hope in the midst of despair over the loss.

Meaning can be sought after bereavement through asking 'why did this happen?' as well as through wider searching reflected by attempts to answer the question 'what does my life mean now?'. Questioning is a common theme in the search for meaning following bereavement and appeared to result in an oscillation between the support gained from their prior meaning structure and a sense of uncertainty following the loss. However, what appears to be important is to challenge definitions of reality, including the explanations provided by others, which are rejected or resisted (Braun & Berg, 1994).

This concurs with recent bereavement theory which focuses on the oscillation between an approach versus an avoidance of grief (Stroebe, Stroebe, & Hansson, 1993). This process of oscillation seems for many to be a constructive process assisting in the development of a reintegrated religious meaning structure

(Golsworthy & Coyle, 1999). There is also a measure of consensus regarding the positive implications of the loss in that bereaved persons found they developed. These include a greater capacity for empathy and understanding of others and an increased sense of the importance of, and involvement with, relationships and human life.

Negativity or anger toward a higher power may indicate the mourner's inability to derive a sense of meaning from the death. When assumptions about the nature of God (as just and benevolent) are contradicted, this incongruity leads to feelings of anger and blame which are directed towards God. However, finding meaning from the death, helps to mitigate some of the sense of anger and is thus able to lessen the severity of the grief response (Williams & Gamino, 1998).

In their research Golsworthy and Coyle (1999) found that a key element of faith was the nature of relationship or connection with God. For some this relationship was intimate and built around trust, while for others their experience of bereavement appeared to shake their faith, leading to questioning and doubt. For most participants, there appeared to be a link between personal support and feeling spiritually supported. In some instances, God was seen as instrumental in the provision of the support, be it from within the family or outside of it, and this increased their sense of spiritual connection.

Klass (2001) has traced the spiritual consolidation of the 'inner representation' bereaved parents make of the child and its validation by the community of others who have suffered similarly tragic losses, which supports the idea that meaning reconstruction is as much a social practice as it is a cognitive process. Bereaved parents are able to get others to know their deceased child through the process of sharing stories and experiences with others. In a sense this is a process of constructing a biography of the deceased and enables the parents to mould the representations they have of their deceased child so that these can have a sense of constancy and stability. Fleming and Belanger (in Neimeyer, 2001) discuss bereavement as 'losing what you have' and how the creation of 'having what has been lost' is the legacy that connects the bereaved to the deceased.



Golsworthy and Coyle (1999) found evidence of a sense of continuity arising through an experience of an ongoing relationship with their partner after death for bereaved spouses. The participants' accounts of their experiences suggest that ongoing relationships with the deceased were not necessarily dependent on being with them but rather on intrapersonal factors. The extent to which there was a feeling of spiritual support and a sense of ongoing presence depended on the meanings attached to these ongoing relationships which can only be regarded as spiritual rather than social in nature.

Klass (1997) has found that parents do not forget the child who died, nor do they wish to. These memories can comfort, but are also painful. They connect the parent to the child and emphasise the importance to them of their role as parents. Rosenblatt (2000) also notes the continued presence of the child in the parent's life in the narratives of bereaved parents. This is achieved through keeping reminders of the child, creating reminders, memories and memorials which are symbols honouring the life of the child.

Continued interaction of parent and child are also common themes in the narratives of bereaved parents. This interaction is quite diverse, sometimes involving feelings and a sense of presence, or having mental conversations with the child. Parents also tend to keep track of the child's timeline as a way of remaining connected to their child, and this may set off recurrent bouts of grief as new losses are encountered, as the parents become aware that each new developmental milestone is yet another that will not be attained by their child. Grieving can also be a way of continuing to be connected with the child and attempts to silence the grieving may be construed as an attempt to break the connection with the child (Klass, 2001). The continuing communication with the child means that the child is still alive somewhere and there is therefore a hope for being reunited with their child in heaven.

Interestingly however, the sense of spiritual support and the connection to God and to the deceased does not appear to lessen the pain of loss. While spirituality or religion may assist the bereaved person in living with the loss it does not reduce the experience of grief. Moreover there is a belief in the permanence of the loss, and an

acceptance that henceforth there will be permanent change (Golsworthy & Coyle, 1999).

According to Marrone (1999) psychological and spiritual transformation for a bereaved parent is likely to occur for the parent after the loss of a child because of the nature of the parent-child bond. He considers this bond to be a sacred rather than contractual bond, which cannot be abandoned if the relationship ceases to be satisfactory, as can happen in marriage through divorce. Even where a parent and child cease to have any contact with one another, they are still connected by virtue of this bond, which defines each participant by the nature of the relationship to the other.

The parent employs three rationales in this process of transformation: reunion, where the parent hopes to be reunited with their child in an after-life; reverence, where the child's death is deemed to serve a higher, perhaps inspiring altruistic social service; and retribution, where the child's death is viewed as punishment for the sins of the parent thus validating the sense of guilt which is commonly experienced (Marrone, 1999).

After the loss of their child, parents are confronted with the task of re-defining the meaning of their own lives, the meaning of the life of their deceased child and the meaning of their relationship to them. In their research Riches and Dawson (1996) found that felt religious belief was a major support and source of reassurance, especially if there is a conviction of an eternal existence.

Some parents find that visiting a medium can be valuable in constructing a sense of specialness of their child, especially regarding some kind of pre-cognition of the impending death or a signal which marked the death. Moreover, those parents who were originally sceptical of these beliefs, admit to revising their original rejection of the possibility of life after death. Sharing of information of mediums and their abilities is one of the more common topics for bereavement support groups (Riches & Dawson, 1996).

According to Rosenblatt (2000) it is to be expected that religion is central in the narratives of bereaved parents because it is a major area of discourse in the culture for dealing with death and the meaning of life. Death is seen as a challenge to religious belief and so the resolution of this challenge can form a significant aspect of the narrative. While not all bereaved parents reach resolution, he has identified seven ways in which this conflict is resolved:

- An affirmation of religious belief while still questioning the death.
- Not seeing God as responsible for the death, and believing that the child is with God.
- Understanding the death as part of God's plan, and that the child's task on earth was completed.
- Not seeing God as responsible for the death, but believing that God chose not to intervene.
- A sense that only a belief in the existence of God makes the loss bearable.
- A rejection of religious language in that death is seen as an arbitrary event.
- A lack of belief in God, in the light of the event.

### **3 Conclusion**

"Life is filled with loss. It is the inevitable in the experience of living. It is inescapable yet necessary for growth" (Arnold & Gemma, 1994, p.3).

Loss is probably an inescapable issue in the life of most people, be it the loss of a precious or meaningful possession, a relationship, or even of a hoped-for event. However, losing someone who is beloved can be so traumatic, intense and shocking, that it can alter the course of existence for the bereaved person for a considerable period of time.

From the literature it appears that the approaches to bereavement are diverse and this is indicative of the diversity of conceptual and philosophical constructs from which they stem and which underlie them. Early research in the field focused on describing

constellations of symptoms and other indicators of bereavement, many employing medical or cathartic models to classify grief.

Despite the differences between approaches, there is general agreement that bereavement provides a notable biographical disruption in the life of the bereaved individual. Furthermore, there is support for the idea that loss of a child is an idiosyncratic discontinuity in the course of a parent's life and that such an event overturns the underlying sense of coherence of existence.

The tendency within human existence is to attempt to create meaning within the framework of a narrative structure so that a sense of stability, coherence and identity can be created for an individual over a life-span. Bereavement, which is a severe disruption of this sense of stability, is the springboard for a process where the individual seeks to re-establish or reintegrate a sense of the meaning of life and of identity in a unified whole. Through the derivation of new meaning or purpose, the extent of suffering is ameliorated. It is through the reconstitution of meaning structures that transformation is wrought into a new understanding of life for the bereaved person without which it would seem difficult to continue to invest in living.

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