

Meaning Reconstruction  
in the Experience of Parental Bereavement

by

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University of Manitoba

A thesis  
submitted to the University of Manitoba  
in partial fulfillment of the requirements  
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MILDRED J. BRAUN

A thesis submitted to the Faculty of Graduate Studies of  
the University of Manitoba in partial fulfillment of the requirements  
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MASTER OF SCIENCE

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## Abstract

In the literature on parental grief, there has been a lack of information regarding parents' experience of understanding, explaining, and finding meaning in their child's death. Through the process of conducting in-depth interviews with ten bereaved mothers, an attempt was made to understand this experience.

Using the grounded theory method of analysis, an explanation of the phenomenon of meaning reconstruction in the experience of parental bereavement was generated. The theory which emerged included three distinct phases: Discontinuity, Disorientation, and Adjustment. Discontinuity conceptualizes the experience of parents who could not account for their child's death in terms of their prior or existing meaning structures (at the time of the child's death) and who could not find adequate explanations for the death. Disorientation was found to be the consequence of Discontinuity. The strategy used to restore meaning in the bereaved parent was conceptualized as Adjustment. Norms which characterized the parents' meaning structure prior to or at the time of their child's death were reinterpreted in order to give meaning to the death.

The findings of this study suggest that the process of meaning reconstruction is a unique aspect of the grieving experience which cannot be explained by existing stage theories of grief. Recognition of the complexity of the process has implications for the community and professionals surrounding the bereaved parent.

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## Introduction

In the period extending from the early 1900s to the present, many contributions have been made to the study of grief. Some examples include the work of Freud, who initially conceptualized grief as a process that occurs over a period of time. Lindemann (1944) later discovered that the emotional experience of grieving causes physical and mental symptoms. In the 1960s, the mourning process, separation from attachment to the deceased, came to be viewed as occurring in phases (Bowlby, 1961). Parkes (1975) identified variables which may predict various types of bereavement reactions.

Much of the research has focused on the experiences of bereaved spouses. Comparatively few studies have focused specifically on the experiences of bereaved parents, despite the fact that child death has frequently been cited as being the most grievous of losses (e.g., Klass, 1986).

The existing literature on parental bereavement has focused primarily on parental reactions to child death, including emotional and psychological responses such as anger (Cook, 1983), guilt (Miles & Demi, 1984), depression (Moore, Gilliss, & Martinson, 1988), sensing a loss of control (Klass, 1988), anxiety (Dyregrov & Matthiesen, 1987), and alienation (Gyulay, 1989), as well as on physical symptoms resulting from bereavement.

Another area of the literature has focused on factors which affect bereavement such as anticipated versus sudden death (Sanders, 1980), mode of the child's death (Miles, 1985), passage of time since

the death (Moore et al., 1988), age of the child (Smith, 1985), and amount and type of support received by parents (Videka-Sherman & Lieberman, 1985).

Although the findings reported in the literature have contributed to a greater understanding of parental grief in terms of descriptions of emotional and psychological consequences, little has been learned regarding parents' struggle to understand, explain, and find meaning in the loss. Evidence of the existence of this struggle appears indirectly in the findings of parental bereavement studies (e.g., Hare-Mustin, 1979; Lehman, Wortman, & Williams, 1987). Miles and Crandall (1983) suggested that parents' search for meaning in their child's death could be a key factor affecting the outcome of grief.

The purpose of this study was to explore how bereaved parents develop an understanding of their experience. Using the grounded theory method, data collected from in-depth interviews with ten bereaved parents were analyzed. The goal of the analysis was to generate an explanation of the phenomenon of meaning reconstruction which emerged from the data and which accounted for each informant's description of their experience.

### Review of Literature

Death is an immanent part of the human experience and has been the target of human thought and analysis since the beginnings of humankind (Crosby & Jose, 1983). Bereavement, defined as the event of a loss, is recognized as an inescapable aspect of the human condition (Kessler, 1987). Grief, the emotional response to the event of a loss, may vary in terms of its implications, severity, complexity, symptoms arising from it, and duration. Although grief is an individual experience, it is shaped by attitudes toward and beliefs about death which are characteristic of the prevalent culture. Experiences may vary across cultures, as meanings ascribed to death differ.

#### Historical Perspective on Grief Research

Prior to beginning the discussion of understanding grief, it should be noted that much of the research in the area has been based on the experiences of bereaved spouses (e.g., Bowlby, 1980; Lindemann, 1944; Parkes, 1972). This may be due to the fact that among the bereaved, spouses are the easiest population to reach. However, findings from this group may or may not apply to other types of bereavement such as the loss of a sibling, loss of a parent, or loss of a child.

Sigmund Freud's (1917/1959) work has been cited as pioneering in the scientific investigation of grief (Pine & Brauer, 1986; Spiegel, 1977). In Freud's view, grief is a process by which a person becomes freed from attachment to the deceased. He used the term "economics of the mind" to describe psychological tasks which

are necessary for the bereaved to accomplish in exchange for "freedom" from the deceased. In a sense, the person's psyche must "work" to cope with the loss. The experience of grieving facilitates the slow and gradual severing of the attachment to the deceased. Through the process, psychic energy of the loss is consumed and the person is freed to become a separate being.

Freud's insight has served to structure the subject of grief as a process that occurs over time and that can be overcome. However, there are weaknesses in his ideas. His terms are obscure and abstract. For example, his definitions for terms such as freedom and psychic energy are unclear. Psychic energy as part of a mechanical process is a concept which has received much criticism. Also, he did not explain how the work of grief is accomplished. How grieving facilitates severing of attachments, how one determines when one has become "freed", and at what point the process becomes complete is not clear from Freud's work.

In the 1940s, Erich Lindemann (1944) systematically studied the phenomenon of grief. In his view, grief had the potential of being experienced as an intense reaction to loss accompanied by physical and psychological symptoms. He described this phenomenon of acute grief as a definite syndrome. Physical expressions of acute grief include tightness in the throat, choking, sighing, emptiness in the abdomen, and tension. Other symptoms such as preoccupation with thoughts of the deceased, guilt, hostile reactions, and unusual conduct patterns were also identified. According to Lindemann, these symptoms can appear immediately after the loss, be delayed or

postponed for weeks or even years. They can also become exaggerated, marked by alterations in the bereaved's conduct, or appear to not occur at all.

He also noted that the bereaved person's personality may be indicative of the severity of the grief reaction. For example, a depressive person may exhibit agitated or more severe depression after the event of a loss. The nature of the relationship was also noted as affecting the severity of the grief reaction. For example, Lindemann reported that severe hostile reactions were evident in persons who were bereaved by someone who had invited hostility, but did not permit expression of it.

Lindemann's study was important because he recognized grief as being a serious condition which affected physical and mental health. Although he identified symptoms of grief and factors which appeared to affect the reaction, his study did not address how such factors as personality, the nature of the relationship, and circumstances surrounding the death might interact to produce various grief reactions. His study was more descriptive than predictive of grief reactions.

Spiegel (1977) summarized a virtual flood of articles on various themes on the issue of death which emerged in the 1960s. During that decade, British psychiatrist John Bowlby focused his analysis on the nature of human attachment and its relationship to the experience of loss, dealing primarily with infant-mother attachment.

He suggested that the original relationship with the deceased continues to be central in the emotional life of the bereaved. He identified three distinguishable phases through which the bereaved person moves in the process of redefining the original relationship with the deceased (Bowlby, 1961). The first of these is characterized by the bereaved person's yearning and searching for the lost figure. Some components of this phase include scanning of the environment -- looking for the person under beds, in closets, and so forth, thinking intensely about the lost person, and calling out for him or her. Signals and sounds are often interpreted as indicating that the lost person has returned. Anger and frustration are typical responses to the fruitless search.

The second phase is described as one of disorganization and despair. Often the loss of a loved one results in the dismantling of old patterns of feeling, thinking, and behaving. According to Bowlby, people in this phase often experience depression and apathy as a result of feeling that nothing from their situation prior to the death can be salvaged.

The final phase of mourning includes reorganization. Having redefined the situation, the bereaved person considers new ways of meeting the demands of life. In a sense, the person aligns him or herself to the changes that have occurred and responds by attempting to resume a social life, learning new skills, or adopting new roles.

In his discussion of the phases of mourning, Bowlby established that an overall sequence can be discerned. He recognized the fact that an individual may oscillate between stages and that his

identified stages are not clear cut. Specific criteria from which to determine which stage a person is in, how long they will be in it, or what factors may complicate or enhance successful movement through the stages were not outlined.

In the 1970s, Colin Murray Parkes (1972) expanded on Bowlby's ideas by including two factors which he believed played a role in the reaction to grief. He used the term stigma to refer to people's attitudes toward the newly bereaved person. He noted that the bereaved person, in a sense, becomes tainted by death; the bereaved person represents the taboo of death. Also, because there are few guidelines in terms of what type of support to offer, many people feel uncomfortable in the presence of the bereaved and therefore tend to avoid them.

The second factor was termed deprivation. This factor refers to the absence of psychological benefits (e.g., love and security) which were provided by the deceased person. In the case of spousal bereavement, loneliness, isolation, and depression may be typical reactions because the companionship of the mate is lost. According to Clayton, Halikas, and Maurice (1972), emotional support from children may be a factor which eases depression.

Parkes went on to discuss physical and psychological stresses which are apparent among newly bereaved persons. He observed that there was an increased risk of ill health among family survivors and close relatives. Psychological pain, or "pangs" and anxiety symptoms were reported as being prevalent after the loss. A "second phase" reaction was characterized by problems focused on issues of

finances and the quality of familial life. Problems of finances may be most relevant in cases of spousal bereavement, because the loss of a spouse may entail the loss of his or her wage.

In a later study of widows and widowers, Parkes (1975) explored the process of grieving by identifying various factors which appeared to affect outcome of bereavement. Through the process of conducting three personal interviews with forty-nine widows and nineteen widowers over a period of thirteen months, it was found that such factors as low socioeconomic status, little warning of impending death, multiple life crises, and yearning were related to what was assessed as being in a poor psychological state. Variables such as the amount of crying, anxiety, anger, expression of feelings to others, and the use of others for support comprised the guidelines from which assessments were made.

The fact that persons from low socioeconomic status groups typically had more young children and were more likely to be divorced and/or evidence alcoholism, may explain why adjustment was rated as poorer for this group than for higher socioeconomic groups. Warning of impending death was explained as a factor contributing to a less severe grief reaction because it provided the bereaved with an opportunity to prepare for the future and possibly make restitution for previous lack of love or understanding.

Multiple life crises were viewed as complicating successful adaptation to a loss because of the secondary effects of additional difficulties involving money, children, or jobs. Subjects who described themselves as yearning and searching for the deceased were



described by Parkes as evidencing dependence and helplessness. A majority of those who rated themselves as "high yearning" saw themselves as crippled without their partner. This may explain poorer adjustment among this group as opposed to the "low yearning" group.

Parkes identified some variables which may predict types of bereavement outcomes over a period of time and attempted to explain why these variables produce their various effects. However, the findings of his study do not explain how the interaction of those variables affects outcomes or what other factors may influence their effects.

In the 1980s, more models depicting grief as evolving through stages were developed (Raphael, 1983; Weizman & Kamm, 1985; Worden, 1982). Raphael included a stage termed "the psychological mourning process". This stage is marked by the period in which the bereaved person reviews and sorts through the bonds of interaction which built the relationship with the deceased. Through the process of reviewing the history of the relationship, bonds are relinquished and the person becomes reintegrated with the world.

Weizman and Kamm (1985) described a phase of "undoing" in which the mourner examines alternatives that could have prevented the death. The bereaved person may hold him or herself responsible for actions that might have been taken to prevent the death, perhaps resulting in feelings of guilt. Phases of anger directed at the person who died, at God, or at the situation and sadness, including feelings of longing and hopelessness, are included in the authors'

model. Integration is the phase in which the bereaved comes to accept the reality of the loss; sadness recedes into the background and the bereaved begins to focus on present concerns.

Worden (1982) included adjustment to a changed environment as a task for the bereaved individual to accomplish. In his view, a component of this adjustment involves the formation of new attachments. He noted that bereaved persons may have difficulty in this area of adjustment because of the possible fear that emotional investment in another relationship may also end in loss. The person may also feel that the deceased is dishonored when he or she is "replaced" with another person. He suggested that mourning is not complete until the bereaved recognizes that other people can be loved without loving the deceased person any less.

According to Worden, a new relationship is necessary. However, it is possible that already existing relationships with friends or other family members may provide adequate emotional satisfaction. It is not explained why a new relationship is the critical factor in signifying the completion of mourning or why a new relationship is mandatory.

This brief overview of some of the theoretical ideas which have been presented in the study of grief illustrates the continued efforts of investigators to develop an understanding of this profound human experience. Bereavement research has progressed from a general description of reactions to death to a more specific understanding of key issues, responses, and tasks of mourning.

### Uniqueness of Parental Bereavement

As has been observed (Miles, 1985; Soricelli & Utech, 1985; Videka-Sherman, 1982), few studies of bereavement have examined issues of parental grief. Yet, of all major life stressors, including the death of a family member, the death of a child in particular has been identified as the most grievous of losses (Klass, 1986; Knapp, 1987; Lehman et al., 1987; Miles, 1985; Videka-Sherman, 1987). Several factors distinguish the loss of a child from other losses, making parental bereavement particularly difficult to resolve.

First, the parent-child relationship is felt to be characterized by unique dynamics. The process of mourning for one's child has been described as not only involving dealing with the loss of the child, but also with a loss of the self (Edelstein, 1984; Kalish, 1981). This conceptualization builds on the Freudian idea that the child is an extension of the self, in which libidinal energy is invested. Theorizing from a psychoanalytic orientation, Schwarz (1977) stated that the child serves to connect the parent to the future, contributing to a sense of immortality of the self in the parent. According to the logic of these ideas, it might be expected that the parent of an adopted child would experience less psychological pain as a result of the child's death than would a natural parent, because the child was not a biological extension of the self. Such has not been shown to be the case. As is characteristic of psychoanalytic theories of human thought and

behavior, the concepts are typically untestable and therefore remain unverifiable.

A second factor, specific to parental bereavement, is the fact that in Western culture, parents typically invest hopes, dreams, and expectations in the lives of their children. These investments are lost in addition to the realistic loss of the loved child. Whereas other types of losses (e.g., the loss of an aged parent) represent the loss of the past, a child's death represents the loss of the future. In other cultures the death of an older person may represent a greater loss than the loss of a child because old age represents wisdom, knowledge, power, and status that has accumulated through many years of life (Ujimoto, 1987).

Third, as Rando (1986) noted, in no other social role are there so many inherently assumed and socially assigned responsibilities as those attributed to the role of the parent. Upon the death of a child, parents are robbed of their identities as protectors and providers, leaving them with a powerful sense of failure. As Edelstein (1984) explained, parenting is based on the premise that actions taken in the present will yield future rewards in the child's life. When a child dies, those rewards are never realized.

A fourth factor which distinguishes child loss from other losses is the fact that in our culture death among children is unexpected. Several researchers have commented on the "unnaturalness" of child death (Rando, 1986; Rosen 1988). In the Western world advances in modern medicine and health care have contributed to greater life expectancy and the lowest-ever infant

and child mortality rates. Most people expect that a newborn child will survive and mature into old age. Inherent in this expectation is the assumption that children will outlive their parents. Kowalski and Bowes (1976) described this perception as a component of our instinctive life cycle expectation.

Edelstein (1984) observed that people have a sense of "rightness" in terms of when the death of a loved one is justified. The death of an older family member can be prepared for intellectually. It makes sense that older people die before children. In fact, death among the elderly is viewed as inevitable. However, when a child dies, peoples' basic trust in the orderliness of life and death as explained by the society's knowledge system is threatened. A child's death cannot be rationalized. There is a loss of the illusion that control, fairness, and protection exist in the universe.

A fifth factor explaining the uniqueness of parental grief is that the attitudes of people in our society about death and the meaning of childhood are contradictory. Death is viewed as a bad act, a frightening happening, a sort of punishment (Kubler-Ross, 1969). Childhood, on the other hand, represents goodness, happiness, and innocence. It is difficult to comprehend that death snuffs out the life of one so undeserving as an innocent child.

The study of the parental bereavement experience is especially warranted considering the fact that child death can strike any family regardless of their socioeconomic status, race, geographic location, or past history. Death is no respecter of these factors.

No family can consider itself to be protected or guarded from the death of a child.

#### Effects of Parental Bereavement

A few authors have addressed responses of surviving children (McCown & Pratt, 1985; McNeil, 1986; Schiff, 1977) and the family as an entire system (Brown, 1979; Hare-Mustin, 1979; Rochester, 1989) to a child's death. However, most of the limited amount of literature on the subject of child death has focused on parental issues.

In the examination of parental bereavement, investigators have provided a description of typical reactions to the death of a child. It should be noted that documented experiences vary greatly between individuals. Although grief is commonly viewed as a process, it does not necessarily proceed linearly toward a fixed end point (Rubin, 1985). Schiff (1977), for example, described the grieving process as a highly personalized balance between expressing grief and fighting it as the bereaved person moves toward the feeling of being capable of facing life again.

Although observers of grief reactions vary in terms of their ideas on how many phases a bereaved person moves through, at what pace they move through, or what factors affect progression through the process, three general phases are typically recognized. These have been useful in providing a guideline in terms of expected responses to loss.

The first phase includes responses of avoidance upon confrontation with news of the death of a loved one. Shock is

experienced as an expression of inability to comprehend the reality of death (Pincus, 1984). Numbness and bewilderment are typical feelings. In a study of maternal bereavement, Edelstein (1984) conducted in-depth personal interviews with 130 mothers who had experienced the death of a child. Many of these women reported that upon hearing the news of the death, they sat or fell down, ran, or screamed. They frequently reported being unaware of their surrounding environment.

After the initial shock of the news, parents have been described as moving into a phase of denial, characterized by disbelief. Many respond by saying "it can't be true". Rando (1986) described bereaved parents in this phase as being confused and disorganized. There may be a reaction of hysteria, withdrawal, or mechanical actions. Intellectually, some may recognize the loss at this point, but may not express an emotional response. Johansen (1988) observed that parents may feel as if they are enclosed in a plastic bubble, watching events from a distance as if isolated from reality. It is suggested that this is a means by which the pain of separation from the child is avoided.

Eventually reality has to be faced by the bereaved parents and a time of intense grief is experienced. During this phase, reactions to the loss are most acute (Rando, 1986). The initial buffering effects of shock and denial on the psyche have worn off and parents come to a full realization of the impact of the loss and some of the implications of it. Extremes of emotions may be experienced.

### Emotional and Psychological Responses

The variety and intensity of emotional and psychological grief responses have been the subject of much of the parental bereavement literature. Research has identified anger, guilt, depression, feelings of a sense of loss of control, anxiety, and alienation among the effects of child loss.

Anger. Anger has frequently been documented as an emotion experienced soon after the realization of the loss (Fish, 1986; Hare-Mustin, 1979; Lehman et al., 1987; Rando, 1986; Sanders, 1980). The emotion of anger over the death of a child may be compared to Kubler-Ross' (1969) description of reactions of people diagnosed with a terminal illness. Common feelings are rage, envy, and resentment. The pressing question at that time is: "Why him/her, why me?"

Anger is expressed in all directions: perhaps at the doctor or medical staff, who are often viewed as having power over death, at the child him or herself for abandoning the family, at God for allowing the tragedy to happen, or at other families whose children are alive. For example, in a study of 145 parents of children who died from cancer, it was found that beyond one year after the child's death, a frequent response of parents was that they felt resentment and jealousy toward other families whose children were living and well (Cook, 1983).

Spouses may also direct anger toward each other, blaming the other for the death. In a study of 112 bereaved parents, Fish (1986) found 30% of husbands and 10% of wives showed a tendency to



blame their partner for the death of the child. As might be expected, this placed a strain on the marital relationships.

Guilt. Another emotion, which has been described as often emerging from anger, is guilt. According to Fish (1986), guilt is the result of anger which has been directed inward to the self. Rando (1986) and Miles and Demi (1984) reported guilt as being one of the most pervasive emotions experienced in grief over a lost child.

As has been discussed, our societal values place great emphasis on the parental provider and protector roles. Ultimately, most parents feel responsible for the well-being of their children. Upon the death of a child, intense guilt feelings may arise as parents contemplate what they could have or should have done to prevent the death from occurring. A sense of failure ensues.

Guilt may also be experienced as a result of parents' feeling of a sense of responsibility for the death due to punishment for perceived past or present misdeeds. Hare-Mustin (1979) reported that upon hearing news of a child's terminal illness, parents often engage in a bargaining process where their good behavior is offered in exchange for the child's life. Parents may view themselves as key figures in the potential recovery of the child. The death of the child is perceived as punishment for failing to meet the standards of the pact. In essence, the parents have failed to prevent their child from dying. In her own personal account, Wyler (1989) described the pangs of guilt and self-recrimination which she experienced as a result of hearing family members explain her

daughter's death as God's way of punishing her for giving birth to a child outside of wedlock.

Through the process of in-depth interviews with bereaved parents, Miles and Demi (1984) identified another type of guilt, termed "cultural-role" guilt. This was described as coming from the parents' feelings of what they "ought" to have done. For example, parents may feel guilt because they did not spend enough time with their child or because they did not resolve a conflict before the death. Almost 50% of the interviewees in the researchers' sample reported feeling this type of guilt.

Depression. Another response to the death of a child is depression. Characteristics of depression include feelings of helplessness, a pessimistic outlook on life, loneliness, emotional pain, and suicidal thoughts. Several authors (Lehman et al., 1987; Miles & Demi, 1984; Moore et al., 1988; Schiff, 1977) found parents to exhibit signs of depression several years after the death of their child.

In Lehman et al.'s (1987) study, 34% of their sample of 41 parents reported that they felt sad or depressed almost all of the time. Anniversary dates (birthday or date of death) and holidays, such as Christmas, were reported as being especially difficult for parents.

Sensing a loss of control. In studies examining parental responses to bereavement, a sense of being overwhelmed and feelings of having lost control were identified in subjects (Cook, 1983; Sanders, 1980). As Johansen (1988) described, the intense emotions

of anger and guilt may be interpreted as signs of "going crazy". Upon the event of the death of a child parents may experience new emotions in intensity as they never have before, causing them to feel unfamiliar with their own feelings, thoughts, and behavior. Gyulay (1989) explained that the roller-coaster fashion of multiple responses to grief may be experienced by parents as signs of insanity. Klass (1988) reported that the first question which parents ask in self-help groups or counseling sessions is: "Is this normal or am I going crazy?"

A sense of powerlessness or helplessness is associated with a sense that one has lost control. Parents may experience a sinking feeling; a feeling that nothing else can be done (Johnson, 1987). Demi and Miles (1988) reported the behavior of bereaved parents as typically confused and disorganized.

Anxiety. In the event of a threatening situation, such as the death of a child, defensive reactions are fear and anxiety. Dyregrov and Matthiesen (1987), in a study of parents who experienced the death of an infant, found that anxiety was experienced as an ever present, gnawing insecurity.

Researchers have found that fear and anxiety after the death of a child are experienced in relation to several factors. Lehman et al. (1987) and Sanders (1980) reported a fear of death itself in bereaved parents. Some parents were afraid that another disaster was imminent. The fact that a tragedy so incomprehensible as the death of a child can and did occur may cause parents to no longer view the world as safe and secure.

Another factor identified as a source of anxiety for parents was concern over their surviving children. Dyregrov and Matthiesen (1987) and Videka-Sherman and Lieberman (1985) found that parents worried about the survival of their remaining children. Recognizing their powerlessness to protect their children from harm, parents may find themselves extremely vulnerable and thus overprotective in an attempt to guard themselves from another loss.

Rando (1986) also noted that parents may experience anxiety about their own behavior in response to the loss of their child. Parents who feel that they are going crazy may feel anxious in terms of their unfamiliar view of themselves. Apprehension of the unknown effects that the child's death will have on the parents' existence, their marriage, and the family as a unit may also increase anxiety.

Alienation. As Gyulay (1989) explained, the intense emotional responses of grief often lead to isolation. The significance of the loss of the child's life in the parents' lives is extreme. Mothers and fathers in Cook's (1983) study described the feeling of loss as overwhelming in intensity. A feeling that life could no longer go on was frequently reported by parents (Edelstein, 1984; Johansen, 1988; Wyler, 1989). When life no longer seems worth living, parents may withdraw from other activities and cut themselves off from social contact.

Parents' obsession with the loss and preoccupation with thoughts of the dead child may cause them to reject offers of support from other family members or friends (Rando, 1986). This may lead to further isolation.

It has also been noted that grief is a highly individual experience. Schiff (1977) concluded that each parent must bear his or her own pain. This may contribute to a feeling of isolation even within the parents' marriage relationship. In the event of a child's death, both parents are struck simultaneously by the tragedy and are burdened with grief. Each parent experiences the loss individually and may be unable to provide emotional support for his or her partner. This may result in feelings of estrangement.

Parental responses to grief are varied in terms of intensity, severity, and expression. The complexity of individual responses is the result of interaction effects. For example, an initial response to a child's death may be one of intense anger. This may manifest itself in a loss of faith in religious beliefs. Anger may also be directed toward the marriage partner in the form of blame, resulting in feelings of guilt. Fear and anxiety may result from parents' view of themselves as going crazy or having lost control, driving them to withdraw from social contact. This in turn may lead to isolation and alienation. Lacking the benefits of community support, parents may feel helpless and depressed. Although research has identified the aforementioned factors as responses to grief, the interplay of these responses within an individual have not been investigated.

#### Physical Symptoms

Another aspect of research in the area of effects of parental bereavement has focused on the physical symptoms resulting from parents' grief experiences. In the 1940s, Lindemann (1944)

recognized physical distress and bodily tensions as characteristic reactions to grief. He viewed the body as responding on all levels to cope with emotional or psychological stress.

Recent research has contributed to a greater understanding of the physical manifestations of grief and the consequences of bereavement on health. In Sanders' (1980) study, which compared the experiences of bereaved parents, children, and spouses, parents were found to exhibit the most physical symptoms resulting from the experience of the loss. Sleep disturbances and changes in appetite were reported to be common problems.

Other physical effects of grief on parents include stomach problems or digestive disorders (Johansen, 1988), weight gain or loss (Gyulay, 1989), lack of strength or physical exhaustion (Rando, 1986), and difficulty in breathing or heart palpitations (Johnson, 1987). Osterweis, Solomon, and Green (1984) suggested that physical changes resulting from internal grief reactions may lower defenses against many diseases. Demi and Miles (1988) found that parents of children who died of suicide as well as parents whose children died in other ways, such as accidental death or chronic illness, reported an increased use of prescription and non-prescription drugs to alleviate physical pain or discomfort.

Lehman et al.'s (1987) findings in a comparison of bereaved parents to a non-bereaved control group contradicted the findings of other researchers. They did not find any significant physical health differences between the two groups. However, it was discovered that a significantly higher percentage of bereaved people

than control group people had died in the period during which subjects were being tracked for the study. These findings suggest that mortality is affected by bereavement, perhaps being an extreme manifestation of grief. The interconnectedness characteristic of the human organism is illustrated in the physical response of the body to psychological and emotional pain.

#### Factors Affecting Parental Bereavement

Another area of literature on parental coping with child death has concentrated on factors which affect bereavement. Some of the factors which have been addressed are: a) anticipated versus sudden death, b) mode of death, c) amount of time since death, d) age of the child, and e) amount and type of support parents received after the death.

#### Anticipated Versus Sudden Death

Lindemann (1944) described anticipatory grief as a reaction that may be experienced in advance of a death (e.g., a possible reaction when a child is diagnosed with a terminal illness and death is inevitable). According to Lindemann, this type of grief may provide an emotional safeguard against the severity of impact of a sudden death. In a sense, anticipatory grief could release survivors emotionally from the relationship before the death occurs. Grief work accomplished while anticipating death may serve to be an important factor in adjustment after the death.

Johnson (1987) and Rando (1986) also contended that parents who have little preparation time for death express more grief symptoms which are more intense, longer lasting, and from which recovery is

more difficult, than do parents who anticipate death for a longer period of time. Rochester (1989) suggested that with appropriate assistance from medical staff, terminal illness grief reactions can be reduced through preparation for the child's death.

Interestingly, other researchers have reported that there are no differences in grief responses between parents who expect the death of their child and those who do not (Klass, 1988; Miles, 1985). In a comparison of sudden versus chronic illness death, Sanders (1980) found that there were no differences in bereavement intensity of survivors between the two groups. The author also found that the length of illness appeared to make no difference in bereavement intensity. It should be noted however, that because reports are retrospective, parents may view their experience in terms of what they have learned to be "proper bereavement".

Soricelli and Utech (1985) in their work with bereaved parents, identified separate phases of grief which parents experience over the course of their child's illness. The first phase occurs at the time when the child's illness is diagnosed. At that time, parents grieve the loss of the child's health. The grief which is experienced at the actual time of death is unique in that the reality of the loss of the child is experienced and parents must deal with living life without the child. The hope for possible recovery has been lost.

A long period of illness may exhaust the parents physically and emotionally, perhaps leaving them especially vulnerable to intense grief experiences at the time of death. On the other hand, it is



also possible that parents experience relief when the inevitable death occurs and a long period of stress comes to an end. Other factors such as how the child views his or her impending death or the type of service and support that is offered to the child and family by medical staff, friends, and family may influence the effect that anticipatory grief has on later adjustment for the parents.

#### Mode of Death

The mode of death of a child has been investigated in terms of the possible differing effects it may have on parental bereavement. The events or circumstances around the death of a child may influence how parents cope.

Schmidt (1986) described the experience of parents bereaved by the murder of a child as being distinct from other types of death. Dealing with the knowledge that someone purposefully caused the child's death is especially difficult. The legal processes pose additional complications. The child's body, as well as his or her possessions, often become property of the state as evidence, causing parents to feel as though the child is no longer theirs. Often court proceedings are lengthy and confusing. For many parents of murdered children, long periods of time may pass before they can begin to rebuild their lives. The additional stress of perhaps fearing for their own lives or the lives of other family members may intensify the grief experience (Peach & Klass, 1987).

Death of a child by suicide has also been recognized as possibly complicating parental bereavement. Many parents must deal

with feelings of guilt that they were responsible in some way or that they could have prevented the death. Rejection, embarrassment, and isolation have been identified as factors resulting in parents feeling desperate and hopeless (Bolton, 1986).

In a study of parents bereaved by a child who had died of a chronic illness, parents whose child had died in an accident, and a non-bereaved control group of parents, Miles (1985) found that there were differences between the bereaved group and the non-bereaved group in terms of emotional symptomatology. However, there were no differences between parents who were accidental death survivors and those who were chronic illness death survivors.

A later study of parents whose children died by suicide and parents whose children died by another mode, revealed that although both groups reported increased health problems, there were no differences in measured levels of emotional distress (e.g., anxiety, depression) or health problems between the groups (Demi & Miles, 1988).

Shanfield, Swain, and Benjamin (1987), in a comparison of parents' responses to the death of adult children from accidents and cancer, found the age of the child to be more strongly related to distress and health complaints than was the mode of death. Although accidental death appeared to be more difficult for parents, it was found that this group of deceased children was younger and more closely tied emotionally to the parents than were children who had died of cancer. It was concluded that the mode of death was not the primary factor determining the intensity of parental distress.

Although there may be certain stressors unique to parents, depending upon the mode of their child's death, it appears that overall grief experiences do not differ significantly across groups.

#### Passage of Time Since Death

Investigators of grief and bereavement have also attempted to describe survivors' experiences with the death of a loved one in terms of phases. Expected durations of these phases have been estimated. For example, the period of depression and intense grief has been described as usually not lasting longer than several months (Bugen, 1977). According to Smith and Borgers (1988), the period extends to approximately twenty-four months.

Many writers have described the pain of grief as lessening over time (Gyulay, 1989; Schiff, 1977; Stoesz, 1983). Others have described the passage of time as facilitating adaptation to the loss. In contrast, Arnold and Gemma (1983) stated that grieving in parents lasts a lifetime. Parents develop a way of learning to live without the child, but remain connected with him or her through their grieving. Nevertheless, the passage of time is an important factor to consider relative to the experience of grieving.

Research studies examining grief reactions to child death have shown that the passage of time does not appear to be related to decreased symptomatology in parents. Miles (1985) reported that the passage of time had little effect in alleviating parents' emotional symptoms, even 30 months after the child's death. Moore et al. (1988) found that two years following the death of a child, parents revealed significantly more physical and psychological symptoms such

as obsessive-compulsive behavior, depression, and interpersonal sensitivity than did those in normal, nonclinical, and psychiatric outpatient comparison groups. The purpose of comparing these groups was to investigate the congruence of bereavement symptoms with mental illness.

Rando (1983) reported an increase in symptomatology in parents in their third year of bereavement. Lehman et al. (1987) described their sample of bereaved parents as still actively dealing with their child's loss and giving little indication that they had "worked through" the loss even seven years after their child's death.

The process of grief has been described as occurring in peaks, valleys, and plateaus rather than decreasing over time (Arnold & Gemma, 1983). Perhaps periods of vulnerability, such as holidays, birthday of the deceased child, or anniversary of the death, are more significant factors in describing the grief process than is the passage of time.

#### Age of Child

The age of a child at the time of death as a determinant of parental grief has been debated by researchers. Rubin (1985) contended that death of a child in the first year of life is particularly devastating for women due to the significance of their role as mother during that time. According to the author, a unique bond is formed between mother and child in the infant's first year of life. Psychological boundaries between mother and child overlap. As normal development proceeds, emotional and psychological

separation occurs. However, if the infant dies at the height of the psychological meld, before separation has occurred, then the unit is shattered with devastating effects on the mother.

Literature describing the emotional distress of parents whose children have died in utero or who have lost children through miscarriage or still birth (Hutchins, 1986; Lietar, 1986; Smith & Borgers, 1988) have negated the notion that the loss of an unborn child is an insignificant experience. As Smith (1985) described, the loss of a fetus has often been minimized. It is often assumed that parents did not have time to develop a personal relationship with the deceased fetus. Based on that assumption, the existence of the unborn child may be ignored or invalidated. For example, rather than stating to parents that their baby is dead, some physicians use the terms "gestationally nonviable infant" to avoid acknowledging the child's death (p. 5).

Smith and Borgers (1988) reported that survivors of perinatal death repeatedly reported that comments such as "you can have another baby" were hurtful (p. 211). In a study which examined perceptions of nurses' behaviors among survivors of stillborn infants, Zalnasky (1989) found that such comments made parents feel that their dead infant was not seen as valued or important and could therefore be replaced.

The loss of a young child may be viewed as being particularly difficult to cope with because parents must deal with their own sense of failure in their inability to protect the child from harm (Rando, 1986). Also, as Rosenblatt (1983) commented, parents of

young children grieve over the loss of hopes for their child's future; a loss of a major investment on the part of parents.

It has also been contended that the loss of an adult child is the most difficult of all losses (Gorer, 1965; Hocker, 1988). Although the death of a child at any age represents the unnatural interruption of the normal life cycle, the experience of losing an adult child may arouse feelings of insecurity in parents; that there will be no one there in the future to take care of them in their declining years. According to Williams (1988), parents may feel anxious about the future, even if other children survive. However, this sense of loss may be especially salient for aging parents who are bereaved by the death of an only adult child.

Despite the controversy over which age at the time of death is most difficult to cope with, there remains a fair amount of agreement among authors that this issue is meaningless to most parents (Johnson, 1984; Rando, 1986; Schiff, 1977). Whereas bereavement situations may differ relative to the age of the child (e.g., losing what might have become of the young child versus losing what had become of the mature child), the experience does not appear to be "easier" or "harder" to deal with at any particular age at the time of death (Macon, 1979).

#### Amount and Type of Support Parents Receive

A frequent response of parents to the death of their child is to withdraw from social contact. Often this isolation from other people and the activities of life leads parents into a state of

depression. Some researchers have examined the role of social support in parents' bereavement.

Bereaved parents have reported a general lack of support from others (Johnson, 1987). Arnold and Gemma (1983) described the community's response to the bereaved family as fearful, perhaps because the event of the death was viewed as being "contagious" in some way. As Rando (1986) noted, the death of a child represents the worst fears of other parents. In response, they attempt to ward off the terror it generates within them by avoiding contact with the bereaved family. According to Klass (1982), our culture has no meaning system into which a child's death can be placed. It represents a form of gross injustice. Neighbors, friends, and family may feel threatened by the awareness that if it could happen to "that" family, it could happen to theirs. This fear may be expressed through avoidance of the bereaved family.

It is unfortunate that many bereaved parents experience a lack of support, considering the findings of research which suggest that support from outside the family unit is beneficial to parents attempting to cope with the loss (Videka-Sherman & Lieberman, 1985). For example, in Edelstein's (1984) study of maternal bereavement, women reported that emotional and social support from friends were helpful in coping with the death of their children. Some characteristics which were described as being valuable in helping included the sharing of the experience of loss with someone who knew and cared about the child, the availability of a friend who listened

and understood, and the performance of specific tasks such as supplying food and babysitting.

Davidowitz and Myrick (1984), in an analysis of "helping statements" offered by people to bereaved parents, found that parents who were asked questions about the deceased child or the family's experience as a result of the death were able to vent emotions. This was described by parents as being helpful.

Support groups. Self-help groups such as The Compassionate Friends, have been described as effective in providing for bereaved parents a sense of unity with others whose lives have also been shattered by the death of a child (Edelstein, 1984; Klass, 1985). Edelstein reported that most of the bereaved mothers interviewed in her sample mentioned that they needed to be with people who had experienced the same type of loss. These women also reported that advice and compassion from others who had experienced child loss were more easily trusted and accepted than what was offered by those who had not had that experience. A support group setting provided opportunities for those needs to be met.

Klass (1985) used the psychoanalytic concept of cathexis to explain that participation in a self-help group is a redirection or transference of some of the energy formerly invested in the child. According to Klass, this is a way of retaining a relationship with the dead child and healing the self.

It is possible however, that similar experiences could be obtained by participation in other activities such as foster parenting, or volunteering. If reinvestment of energy is actually



occurring, it remains to be proven that this is effective in helping parents to adjust to loss. Klass (1985) did not consider, for example, that continued energy investment in a dead child may prevent or inhibit investment in new relationships or activities. It is possible that this could have the effect of complicating rather than assisting in adjustment to loss.

#### Summary

In this review of literature in the area of bereavement and grief and more specifically parental reactions to child loss, a general overview of characteristic grief responses has been provided. Much of the literature is anecdotal in character (Edelstein, 1984; Klass, 1985; Schiff, 1977). The focus of these sources has been on the individual experiences of parents as they describe them, without the use of questionnaires or other instruments.

The literature describes reactions to grief as occurring in discernible phases, giving some indication as to what may be expected of a bereaved individual after the loss of a loved one. For example, a period of avoidance is expected after the initial news of death, often followed by a period of denial, until at some point the reality of the death is faced and efforts at coming to terms with the loss and the new situation are made. Although the labeling of phases helps to structure the grief process in terms of what is expected, there is a danger in assuming that all people must pass through all phases and in the order that they are specified.

At this point in the investigation of grief responses, many questions have not been answered in the research. For example, how long do people stay in a particular phase of grief? What factors influence the pace at which people progress? What determines the intensity of emotions experienced? What factors operate to cause a person to progress or regress in the process of bereavement? What criteria determine when the mourning process is complete?

Some research has provided information regarding typical effects of bereavement. Although some typical responses that have been catalogued include anger, guilt, depression, a sense of loss of control, anxiety, and alienation, an understanding of the interaction of those responses within individuals has not been addressed. For example, guilt has been described as emerging from anger. Is guilt experienced without anger in some individuals? Do some responses occur as a result of others, or are they experienced as separate emotions? Would alleviation of the symptoms of one response, such as alienation, have the effect of relieving symptoms of another response, such as depression?

Another area which has been explored includes factors which may affect bereavement. In reviewing the available literature, it has become apparent that factors such as anticipation of death versus unexpected death, mode of death, time since death, and the age of the child at the time of death are not reliable predictors of type or severity of grief. However, support from outside of the family from neighbors, friends, or a support group has been demonstrated to be helpful to bereaved parents. Factors such as what type of

support is most effective, how much support is needed, at what times it is needed, and how to offer it effectively, require further investigation.

Although it has been recognized that parental bereavement is a distinct form of grief, perhaps even the most difficult to resolve, it has not been determined that this holds true in other contexts such as other cultures where child death is a relatively common phenomenon, or in pathological families where children are abused or neglected.

#### Phenomenological Theory

In the study of parental bereavement, a phenomenological theoretical framework is useful in understanding the grieving experience. A phenomenological approach permits the investigator to describe how individuals structure meaning relative to their experience in the world (Luckmann, 1978). In essence, a phenomenon is analyzed in terms of how it is lived and experienced (Cochran & Claspell, 1987).

According to Berger and Luckmann (1966), the experience of reality and all knowledge are socially constructed as a consequence of interaction. Through interaction humans produce a social world which is experienced as an objective reality. This created world acts back upon the humans who were producers of it. The validity of what is experienced or believed to be "real", or what is "known" to be true, is not an issue. In other words, determining whether or not what a person believes to be true is actually true is irrelevant.

As Berger & Luckmann (1966) explain, reality is experienced in the most intense manner in everyday life when one is in the state of being "wide-awake". Individuals participate in everyday life, in which routines and patterns of behavior have meaning and serve to orient the person in the objective reality. Knowledge guides conduct in everyday life, which is knowledge experienced as common sense. Everyday life experiences are interpreted as objective reality, which is subjectively meaningful in that the world makes sense. Additional verification is not required because, as the authors explain, everyday life is "simply there, as self-evident and compelling factity" (p. 23).

This understanding of reality is one which is shared by others. As Berger and Luckmann (1966) describe, the meanings and natural attitude of the individual correspond with those of others. In essence, the individual, along with the others in his or her society, share a common sense about the reality of the world. The world is experienced in the context of order, direction, and stability.

Human activity becomes habitualized as actions are frequently repeated. Habitualized patterns are typified and meanings attached to behavior patterns are shared by members of the particular social group. The attachment of meaning to activity forms institutions, which are viewed as having a reality of their own. Meanings develop through human interaction. Beliefs, values, and norms, which are commonly shared by members within a society, become characteristic

of a culture. The collection of meanings created through human interaction form the social world.

Being available to essentially all members of a society, these shared meanings become part of the social stock of knowledge and are taken for granted. Because the individual "knows" his world and experiences it as the "real" world, the functioning or malfunctioning of it is explained in terms of the "knowledge" the individual has of it. Meanings of experiences are "fit" into a consistent framework which is shared with others. The subjective reality of the individual must "stand in relationship" to the objective socially defined reality (p. 149).

As Berger and Luckmann (1966) contend, all social reality is precarious. The constructed reality is in constant threat of collapse. There is always the possibility of the occurrence of a crisis; events which cannot be "explained". The fear of unexplainable events is evidenced in peoples' avoidance of the topic of death and its surrounding mysteries such as what the purpose of our existence on earth is. A natural disaster such as an earthquake may also be experienced as a crisis, because the occurrence of it has not been incorporated into peoples' reality structures. When a crisis presents itself, "knowledge" does not explain the event satisfactorily. The crisis portends the disconfirmation of reality.

The total disconfirmation of reality of which Berger and Luckmann write, is illustrated in Victor Frankl's (1963) personal account of his experiences as an inmate of concentration camps in the second world war. He described how he was cast into a world in

which all aspects of his former life (as a man, a husband, a doctor, and so forth) no longer had meaning. In the camp, he was "under the influence of a world which no longer recognized the value of human life and human dignity, which robbed man of his will and made him an object to be exterminated ... under this influence the personal ego finally suffered a loss of values" (p. 49).

He further described the effect of the camp-world as causing the inmate to think of his existence as having descended to the level of animal life. His own existence as a human being lost its meaning. Each prisoner was stripped of all his belongings, including the hair from his body. Even the reality of the individual's identity was disconfirmed when his name was replaced with a number. As Frankl (1963) stated, "...all we possessed was our naked existence" (p. 13). Nothing was left which linked the prisoner to the meaning and purpose of his former life. He was subjected to a world of degradation, brutality, and injustice; a world in which he had no reason for living.

Because an individual's subjective reality must confirm the objective reality, there is a need for the individual to re-orient himself when confronted with a situation that challenges the "fit". In other words, if there is a fracture in his understanding of reality; a problem or crisis of which he cannot make sense in terms of the shared socially constructed meanings, he attempts to integrate or reconnect himself to reality in order that meaning be restored. He attempts to make sense of his experiences which cannot be explained in terms of his understanding of the world.

In the extreme case of Victor Frankl, no meaning or sense could be derived in the world of the concentration camp. However, Frankl discovered that he could find meaning in his ability to decide to preserve his inner mental and spiritual self from the powers of circumstances which surrounded him. Meaning could be found in suffering as an inevitable aspect of human life. Subjected to the direst of circumstances, Frankl entirely reordered his reality to find meaning in his existence.

Others who lost hold of the meaning in their existence became subject to physical and mental decay. This decay occurred suddenly in the form of a crisis. The inmate would simply give up. No threats or physical blows would affect him. As Frankl (1963) described, "...there he remained, lying in his own excreta, and nothing bothered him any more." (p. 74)

#### Application of Theory to Parental Bereavement

Many concepts of phenomenological theory can be applied to the experiences of parents who have experienced the death of a child. As explained earlier, we are born into a world which we experience as objective reality. Our everyday experiences "make sense" to us when interpreted against these socially provided meanings and are routinely taken for granted. Meanings are shared with others who also have a common sense attitude about the sensibly ordered real world.

In this world, people have beliefs, assumptions, values, and norms that "make sense" of the order of the world. For example, there is a common sense attitude that children in our society will

mature to become adults. Speculation regarding a child's future does not revolve around the condition of "if" he or she grows up, but rather "when". The maturing of a child to adulthood is a natural part of life.

As part of the natural order of the world, it is "known" that children out-live their parents. Parents come from their own past, bring forth children into the present, who will then carry on into the future. This pattern follows the "laws of nature". Corresponding with the laws of nature is the "knowledge" that children do not die.

In our society, when a child dies, the natural order of things as we know it is challenged, as opposed to past centuries or other contemporary cultures. Westerners today do not expect children to die. In fact, it is believed that through medical knowledge and technology, child death has been conquered (Arnold & Gemma, 1983). When a child death does occur, parents experience a shattering of their world. A world that was once experienced as secure, becomes unjust, unfair, anomic, and out of control: unintelligible.

#### Attempting to Explain

Although not directly addressed in empirical studies, it appears that a frequent initial response of parents to the death of their child is to ask the question "why?" (Craig, 1977; Hare-Mustin, 1979; Wilson, 1988). In Lehman et al.'s (1987) interviews with bereaved parents, it was found that 91% of the 41 interviewees reported that they had asked the question: "why me/why my child?". Sanders (1980) reported that the question of "why?" was an



"obsessive rumination" as parents attempted to explain the mystery surrounding the fact that their child had died (p. 317). This response was noted from parents who survived a chronic-illness death as well as those who survived the sudden death of their child.

In their attempt to develop a model of parental grief, Klass and Marwitt (1988) described how parents frequently attempt to recreate the circumstances surrounding the death in order to determine its preventability. This behavior was viewed as the parents' need to explain why the death occurred.

In an investigation of family adjustment to sudden infant death syndrome, May and Breme (1982) suggested that it is essential that medical professionals explain to parents that their child died of a "recognized though imperfectly understood syndrome" rather than of an "unexplained" death, in order to reduce parents' feelings of self-blame. This suggests that dealing with the question of "why?" is a significant issue faced by parents.

In the search for an explanation, parents often blame themselves. In Lehman et al.'s (1987) study, 62% of bereaved parents reported that they found themselves thinking: "if only I had done something differently it wouldn't have happened". Parents may also explain the death as punishment for real or imagined offenses committed against God (Craig, 1977; Klass, 1982; Wyler, 1988).

The search for an answer to the question "why?" demonstrates the human propensity to make sense of their experiential world and to interpret events in terms of the meanings that are part of the

social stock of knowledge. When a crisis damages the parents' understanding of the world to such an extent that no available explanations fit, meaninglessness follows, resulting in a world that no longer makes sense.

#### The Meaning-Less Experience

According to Klass (1982), parents initially search for reasons to explain their own child's death, but often begin to ask "why?" in a more general sense. For example, parents may ask why it is that children die. A theme which emerges from the limited available literature is that bereaved parents experience difficulty in finding meaningful explanations to answer their questions. Lehman et al. (1987) discovered that 59% of the sample who had asked "why me/why my child?" reported that no sense had been made of the death.

As Rando (1985) explained, parents may experience a profound sense of disillusionment and a feeling of injustice when previously held beliefs and values about life no longer offer security. Life may come to be viewed as senseless when expectations of what is just and reasonable are shattered (Arnold & Gemma, 1983). Berger and Luckmann (1966) termed the experience of loss of norms and meaning "anomie". Parents in Dyregrov and Matthiesen's (1987) study of infant death survivors, reported that since the death of their child, they no longer viewed the world as a safe place in which to live. In their view, it had become a place full of uncertainty, fear, and insecurity.

Hansen & Cannon (1984) used the analogy of a rug being pulled out from underneath them to describe parents' feelings after the

death of a child. The death is experienced as a threat and a challenge to beliefs about the natural order of the world. A sense of trust in the organization of the universe is undermined.

Sanders (1980) reported that several of the parents in her study of bereavement reactions spoke of moving through an unreal world in which life did not make sense. It is possible that the experience of feeling a loss of control or going crazy, as was addressed previously in the literature review, is related to the perception of the world as no longer being just, orderly, or secure.

#### Resolving Meaning

According to phenomenological theory, human beings cannot exist in a world in which there is no meaning. As Frankl (1963) observed, there is no reason to go on living if there is no meaning. The world must be restructured to restore meaning, or the only alternative is suicide. Parental reactions of suicidal thoughts and behavior following a child's death have been reported (Edelstein, 1984; Gyulay, 1989; Wyler, 1988). It is clear however, that despite the fact that many beliefs about the world's order may have been destroyed, many bereaved parents decide to go on living. In order to do so, they must restore meaning to their lives.

Basic to Berger and Luckmann's (1966) theory is the idea that in response to damaged experiences of reality, human beings struggle to reorder their reality to accommodate what previously did not "fit" with their understanding of the world. The death of a child eradicates the ground of the meaning structure by which parents assimilate their reality. The structure must be reorganized in

order to incorporate the new reality that one's child has died and that life will continue in absence of that child, despite the belief that it should not be that way (Benoliel, 1985; Klass, 1988).

The incorporation of the child death experience into the meaning structure varies widely among individuals. One couple, described in the literature, found meaning in the presence of mourning doves outside of their window, which to them represented the continued presence of their deceased daughter. Another family found meaning in the symbol of a rose on the child's grave which stayed alive for two weeks in the cold month of February. This was perceived as being a sign from God that the child was safe (Coffel, 1989). This example illustrates the family's apparent need to believe that "someone" is in control.

Other bereaved parents reported finding meaning in a changed view of life. Experiencing the death of a child may instill a sense of tentativeness and fragility of life which causes a reordering of priorities. As one woman reported in Klass' (1985) participant observation study, "...life is too short to live doing things you don't want to do" (p. 245). A participant in Dyregrov and Matthiesen's (1987) study reported that his beliefs about the future had changed since his child's death. Consequently, he no longer planned a long time ahead.

Videka-Sherman and Liebermann (1985) discovered that many parents, after having experienced the death of a child, reported changes in value and belief systems. Increased value was placed on

interpersonal relationships. As one subject stated: "people matter more than possessions" (p. 81).

Other parents have reported finding meaning in their bereavement experiences through religious beliefs. As Wuthnow, Christiano, and Kuzlowski (1980) explained, religion as a sub-set of shared meanings, locates bereavement within an interpretive framework in which suffering can be understood. For example, death is incorporated as a meaningful element of existence. People who believe that God has the ability to use death to good purpose may, in time, perceive the experience of bereavement as providing benefits. For example, their understanding of God's love may be increased, they may discover a greater concern for others, or may discover new insights about themselves.

As Schiff (1977) noted, a belief that death is part of a divine plan can provide hope for grieving parents. The belief in life after death can also provide meaning in that death is viewed as part of a larger purpose; indeed it is not meaningless or pointless.

In Videka-Sherman's (1982) study of bereaved parents' coping strategies, religiosity was associated with growth and decreased negative affect. Content analysis of parents' responses to questions regarding the effects of the bereavement experience was the method used. The author suggested that although religiosity was not associated with decreased psychophysical depressive symptoms, it did provide parents with help in gaining an understanding of the meaning of loss.

Helping others has been identified as providing meaning to grieving parents. In a study which examined the functions of self-help groups in the healing process of bereaved parents, Klass (1985) reported that numerous parents described the act of helping other grievers as providing meaning to the death of their child. As one member stated, "...if you feel you can do something for someone else it gives meaning to all your heartache" (p. 361). According to Videka-Sherman (1982), altruism, which was defined as "volunteering in any capacity to help other parents facing the death of a child" (p. 690), was associated with decreased depression over time.

#### Statement of the Problem

As was previously outlined in the review of parental bereavement literature, empirical investigation has focused primarily on descriptions of reactions of parents to child death and on factors affecting bereavement (e.g., age of the child, mode of death). Although much has been learned about the emotional and psychological ramifications of child death, little has been discovered about the struggle of parents to understand and find meaning in the loss as they attempt to "place" the experience. As Miles and Crandall (1983) suggested, this search could be a key factor affecting the ultimate outcomes of grief.

According to Rubin (1985), the bereavement reaction is judged to be complete when functioning and personality characteristics have resumed to the pre-loss state. This type of standard implies that if the bereavement process is successfully resolved, the person will be the "same" as he or she was before the death. According to

phenomenological theory, it is doubtful that after experiencing a reality-threatening experience such as the death of a child, that a person would remain unchanged.

The focus of the present study was directed away from the isolation of variables that are predictive of grief reactions, toward an exploration of ways in which the bereaved develop an understanding of their experience which incorporates or accommodates the new reality. Changes in parents' structures of meaning were investigated through the process of conducting in-depth interviews.

## Methodology

### Qualitative Research Using Grounded Theory

Phenomenology is a theoretical perspective by which meaning structures of individuals' experiences of life are examined. A phenomenon is studied in terms of how it is lived and experienced. Qualitative research is useful for this type of study because it lends itself to description and analysis of parents' experiences and interpretations of child death.

In a qualitative research approach, data are collected in the form of personal descriptions of individuals' experiences of a particular phenomenon. These descriptions of reality permit the investigator to capture the complexities of the experience. Such reports of experience are not amenable to quantification.

Rather than attempting to establish causality or relationships among variables derived from pre-existing concepts or hypotheses, the approach used for this study was designed to identify components involved in the process of meaning restoration among bereaved parents. Because of the exploratory nature of this study, a qualitative research approach was selected.

The particular method of qualitative research which was used for this study was Glaser and Strauss' (1967) Grounded Theory method of analysis. This is a systematic approach of analyzing qualitative data with the purpose of generating explanatory theory. Specifically, the method is based upon the process of constant comparison of concepts which are derived from data. Similarities



and differences between concepts are noted and similar concepts are clustered into categories.

Concepts and categories are continually produced, combined, and recoded to reflect the substance of what is in the data. Through the entire process of constant comparison, the data are analyzed for patterns or relationships between the concepts, which explain the variation within the data. The goal of this method is to develop a common account from all the data that is "faithful to each individual description and reflects the phenomenon under investigation" (Cochran & Claspell, 1987, p. 39).

The emphasis of this method is on the process of theory generation, not on verification of theory, although the latter aspect is subsumed by the theory generation process. A more detailed explanation of this process follows in the Data Analysis section.

#### Data Collection

##### Grounded Theory Method of Sample Selection

The criteria used for selecting a sample in a grounded theory study differs from that typically used in hypothesis testing research. First, rather than selecting a representative sample on the basis of critical variables, the grounded theory sample is selected from a population in which individuals are known to experience the phenomenon under investigation.

Second, in a grounded theory study, there are no specific criteria for the number of cases which are necessary to achieve the goal of establishing relationships between categories. What guides

the investigator, in terms of selecting the amount or type of data to be analyzed, is the seeking out of variation of the categories which emerge from the incoming data. The purpose of this is to facilitate the development of theory which accounts for a wide range of variation in people's experience of a phenomenon.

Recruitment of the sample. To examine the experience of parental bereavement, the sample for this study was obtained from a local chapter of a support group for bereaved parents, The Compassionate Friends. The leaders of this support group were contacted and informed about the purpose of this study. These leaders expressed an interest in this research and offered their assistance in identifying individual members of the support group who would be willing to participate as informants.

A letter (see Appendix A) which outlined the purpose of the study and requested volunteers was distributed to each of the participants at one of the group's monthly sharing meetings. The investigator attended that particular meeting and also verbally requested volunteers. At the end of the meeting, a "sign-up sheet" was placed on a table in the room for volunteers to identify themselves.

The leaders of the support group also mailed a copy of the letter to other members who had not attended that particular meeting and included a request for participants in the chapter's monthly newsletter. Arrangements to conduct an interview were made with ten of the parents who identified themselves as willing to participate.

Characteristics of the sample. All of the informants who participated in the study were bereaved mothers who had been contacted because of their association with The Compassionate Friends support group. Each of these mothers had survived an unexpected loss of their child.

Several characteristics of the sample are important to note as they may have affected the quality of the data obtained. First, participants volunteered to participate in this study and therefore were likely prepared to speak freely about their experience. Second, the interviews were pre-arranged which allowed participants time to prepare themselves to discuss the aspects of the experience which were most relevant to them. Third, all of the informants had participated in the support group in which monthly "sharing meetings" are held. This experience likely allowed them to be comfortable about sharing their experience with the investigator. Fourth, the investigator posed the question: "Will you tell me the story of your experience of losing your child?" which allowed the informants freedom to express what was important to them. A profile of the informants is included in Table 1 on the following page.

Table 1

Informant Profile

INFORMANT #1	Length of time since death: Age of child at time of death: Age: Surviving children:	6 yrs, 7 mos. 12 yrs 46 yrs 1
INFORMANT #2	Length of time since death: Age of child at time of death: Age: Surviving children:	1 yr, 5 mos. 25 yrs. 58 yrs 0
INFORMANT #3	Length of time since death: Age of child at time of death: Age: Surviving children:	2 yrs, 4 mos. 24 yrs. 50 yrs 1
INFORMANT #4	Length of time since death: Age of child at time of death: Age: Surviving children:	7 mos. 18 hrs. 26 yrs 0
INFORMANT #5	Length of time since death: Age of child at time of death: Age: Surviving children:	7 yrs, 6 mos. 5 mos. 39 yrs 2
INFORMANT #6	Length of time since death: Age of child at time of death: Age: Surviving children:	2 yrs, 7 mos. 19 yrs. 46 yrs 6
INFORMANT #7	Length of time since death: Age of child at time of death: Age: Surviving children:	8 mos. 17 yrs. 42 yrs 0
INFORMANT #8	Length of time since death: Age of child at time of death: Age: Surviving children:	10 yrs, 9 mos. 16 yrs. 57 yrs 2
INFORMANT #9	Length of time since death: Age of child at time of death: Age: Surviving children:	6 yrs, 8 mos. 4 mos. 30 yrs 3
INFORMANT #10	Length of time since death: Age of child at time of death: Age: Surviving children:	1 yr, 8 mos. 5 gestation mos 31 yrs 0

### Technique

Data were collected using the technique of an unstructured, open-ended interview with each of the participants. The interviews were conducted in a private setting, most often in the informant's home. The entire interview was tape-recorded. The length of the interviews ranged from one to two hours. Individuals were informed of their freedom to ask questions and that there was no "right" or "wrong" way of presenting their story. The purpose of this type of interview was to acquire detailed, in-depth information from the respondents' own words (Swanson, 1986). Also, the unstructured nature of the interview allowed the investigator to explore the territory of the respondents' experience and to be directed into anticipated or unanticipated areas (Field & Morse, 1985).

At the onset of each interview, informants were asked to tell the story of their experience of losing a child. Informants were also informed that no pre-formulated questions would be posed. Rather, they were requested to discuss those aspects of their experience which were important to them. At certain points throughout the interviews, respondents were asked to elaborate on or clarify certain statements. The role of the investigator throughout each interview was to focus on the development of the concerns and viewpoints of the informant. This ensured that the investigator did not influence the informant to confirm pre-conceived hypotheses.

### Ethical Considerations

After the self-selected individuals were contacted, a convenient time and place to conduct the interview was chosen.

Prior to the onset of the actual interview, informants were requested to sign an "Informed Consent" form (see Appendix B), indicating that they agreed to participate in the study under certain conditions. This form reiterated what had been outlined in more detail in the letter which was first distributed at the monthly sharing meeting.

Essentially, by signing the Informed Consent form, participants agreed that they would participate in the study providing that specific conditions were met. First, the tape recording of the interview would be destroyed immediately after the interview had been transcribed. Second, participants' identities would remain confidential and names mentioned in the interview would be deleted or substituted with pseudonyms. Third, informants would have the opportunity to edit the written transcripts of their interviews to meet their approval before the data were analyzed. A form (see Appendix C), which requested informants to indicate which revisions they wished to make, was included with the transcript. Informants signed the form, thereby agreeing that providing the requested changes were made, the transcript could be used for data analysis. Signed forms were returned to the investigator by each of the ten interviewees.

Fourth, the list of names which identified the informants would be destroyed after the transcripts had been edited. Finally, informants were informed of their freedom to withdraw from participation or to withdraw information at any time during or after the interview.

A letter (see Appendix D), which explained the purpose of the study and the specific procedures of data collection, was submitted to the Research Ethics Committee of the Faculty of Human Ecology, University of Manitoba. Approval that the appropriate ethical criteria for research involving human subjects had been met was obtained (see Appendix E).

#### Data Analysis

Each of the ten tape-recorded interviews was transcribed word for word. With the use of the computer program, QualPro (Blackman, 1991), a text database and productivity tool used for qualitative data analysis, the texts of the recorded interviews were prepared for analysis. A blank line was left between speakers. Pauses or gaps in the interviews were indicated with dashes. Exclamations such as crying or laughter were also indicated. Each page was coded to allow only the investigator to identify the interviewee (Field & Morse, 1985).

QualPro is designed so that each of the lines of the transcript is numbered. Lines or blocks of text are coded with a conceptual label. The code and its corresponding line numbers are stored in the computer's memory. Codes which identify text segments can be multiple, overlapping, embedded, or nested. In this sense the program accommodates the need to account for the complexities within the data. Coded segments are also easily sorted, retrieved, compiled, and recoded. This allowed the investigator flexibility in the process of manipulating the large volumes of text.

### Strategies for Developing a Grounded Theory

Initial coding. The first step in the analysis of data is the reduction of raw data into concepts. This process is defined as coding. As described by Charmaz (1983), in the initial phase of the coding process the data are carefully read. Through line-by-line accounting, the investigator searches for what can be defined and discovered in the data. A code which represents the concept of what was stated in the text is assigned to that particular segment. For example, the text "And the odd time I'd be sitting there and another boy would go by, and I'd look at him and think: why wasn't it him instead of C?" was coded with the term "why". The code "why" was defined as references which informants made to questioning why their child died, or why the death happened.

All of the data were coded in this manner to ensure full theoretical coverage (Chenitz & Swanson, 1986). Two assistants who had previous experience with coding qualitative data participated in the initial coding phase. Their assistance at this stage was useful because it increased the investigator's awareness of issues identified in the data. Because of the required familiarity and sensitivity to the data, the remaining phases of analysis were conducted only by the investigator.

As codes were being constructed, they were continuously compared to the entire interview as well as to other interviews to identify similarities and differences in terms of what was said or meant by the informant (Field & Morse, 1985). In this part of the process, as through the entire process of conceptualizing the data,



memos were kept. As Corbin (1986) defined them, memos are the analyst's written records of the analytical process. For example, it was recorded that one informant referred to the fact that she had trusted in the belief that if she would "do things right", that things in her life would "work out". This was noted to be similar to a comment of another informant who stated that after her child had died, she felt that she had lost control of her life. The similarity between these two statements was recorded in the form of a memo. These were the beginning characteristics of the larger concept "perceived control".

In the process of initial coding, approximately 100 codes were developed. Some examples of initial codes are included in Appendix F. Codes were continuously compared and clustered on the basis of commonality. Codes were also continuously redefined as they were compared to other segments of data. For example, an initial code which was developed from the data represented references which the informants made to their own death. After comparing all of the segments which were labelled with this code, it became apparent that some segments represented the informant's desire for their own death because of a lack of purpose to go on living after their child's death. Other segments of data which were coded based on a reference to their own death were found to be representative of a desire to become united with the deceased child through their own death. Much later in the analytic process, informants' references to their death because of a lack of purpose in living became subsumed under the key category, Disorientation. References to their own death which

referred to a desire to become reunited with the deceased child became subsumed under the category, Adjustment.

Focused Coding. In the focused coding phase, codes which were initially developed were continuously compared to each other and sorted on an analytical level, not merely for the purpose of summarizing the data. In this phase, concepts were grouped together in terms of patterns or clusters of similar meaning. The concepts which became subsumed under a greater abstracted concept, or a category, formed the theoretical properties of that category. For example, the codes which represented informants' reported experiences of feeling out of touch with others and the world, that their view of life had changed, and that they had lost their sense of a purpose, became subsumed as properties of the key category, Disorientation. The relationship of these characteristics of Disorientation, to another key category, Discontinuity, is that they are the resulting effects or consequences of a prior meaning structure which does not account for their child's death (Discontinuity).

Throughout the analytic process, categories were developed and "densified" by defining and "dimensionalizing" their properties (Glaser & Strauss, 1967). For example, one of the properties of the category, Prior Meaning Structures was the informants' perception of the nature of life. This represented parents' views of life as being basically good in nature on one end of the continuum, to a recognition of life as being characterized by hardship and difficulties on the other end.

Conceptual order from the mass of data was obtained through the process of making linkages between categories by examining how they were related. As Glaser (1978) suggested, linkages among categories can be developed by asking the following questions: What causes certain consequences? Under what conditions does the cause result in the consequence? In what context does the condition occur: Is one category contingent upon another category? Do any categories co-vary (i.e., does one category change with the changes in another category)?

Again, it should be noted that memos which recorded the analyst's emerging hypotheses about relationships between the categories were written throughout this phase (see Appendix G for an example of a hypothesizing memo).

In the process of theory development, the process of reduction of terminology (Glaser & Strauss, 1967) was used. Reduction means that underlying uniformities in the initial codes and categories are sought and subsumed under higher level concepts. For example, references made by the informants that they questioned a) what they could have or should have done to prevent the death, b) what others could have or should have done, and c) what possible reason there could be for the death, became subsumed under one category. The underlying uniformity between these references was that they all indicated the parents' attempts to explain the death of their child.

Saturation of the categories was achieved when all of the data had been accounted for and were subsumed under higher level

concepts. At this point none of the data pointed to new aspects which had not been conceptually represented in the theory.

Through the process of constant comparison and reduction, the core category emerged. This was the category around which all of the other categories revolved. In essence, the core category represents the main storyline of the data and accounts for the variation within the data. The core category in this study was the nature of parents' prior meaning structure. A meaning structure which accounted for the child's death resulted in a lack of a need to explain the death, a low degree of disorientation, and little required adjustment to the existing meaning structure. On the other hand, a meaning structure which did not account for the child's death resulted in a need to explain the death, disorientation, and required adjustment of the prior meaning structure.

The main goal of this research was to generate theory which explained the process of meaning restoration in the experience of parental bereavement. The theory which emerged was grounded in the data. It should perhaps be reiterated that the data collected in this study were not used for the purpose of providing evidence or verifying hypotheses of the theory. The vital job of testing the generated theory remains for future research.

## Findings

Typically in quantitative research, hypotheses are developed and tested and findings of those tests are presented in the results section of a research report. The purpose of a grounded theory study differs in this regard, as the aim of the investigator is to present the generated theory of the phenomenon under study, not to prove or disprove hypotheses (Glaser & Strauss, 1967). As suggested by Antle-May (1986), the following presentation of the findings includes segments of actual data which are used for explanatory power as well as existing literature which are integrated with the theoretical scheme. Therefore, there is no separate discussion section. A final section will present implications of the findings and questions for future research.

### The Research Question

As previously stated, the purpose of this study was to explore the ways in which bereaved parents develop an understanding of their experience of child loss. Through the process of interviewing ten bereaved mothers, it became apparent to the investigator that although all of the informants expressed a great sense of loss, pain, and difficulty in their experience, there was variation among them in terms of their interpretation of the meaning of the loss. It should be noted that grief as an emotional response to the death was reported as having been experienced by all of the informants. The important distinction between the various informants was found in terms of the meaning which they attributed to the death, not in terms of the amount or degree of emotional pain they experienced.

The investigator focused primarily on the story of one informant which differed significantly from the others in this regard, to formulate the more specific research question: Why did one informant openly express complete and immediate acceptance of the loss, whereas other informants expressed great difficulty, even over extended periods of time? This was the main theme of all the data collected from the ten interviews.

#### Overview of the Theoretical Scheme

As stated by Glaser (1978), the analyst must constantly and consciously search for the core category throughout the phases of data collection and coding. This sums up the substance of what is occurring in the data. Through the process of conceptualizing the meaning of words, phrases, and statements of the informants, comparing incidents and concepts to each other, grouping them into categories and subcategories, identifying properties of those categories, and linking them together in terms of conditions, consequences, and strategies, the core variable emerges. This is the category around which all of the other categories revolve, or meaningfully connect. The core category is central in that it accounts for a large portion of variation in the stories of the informants.

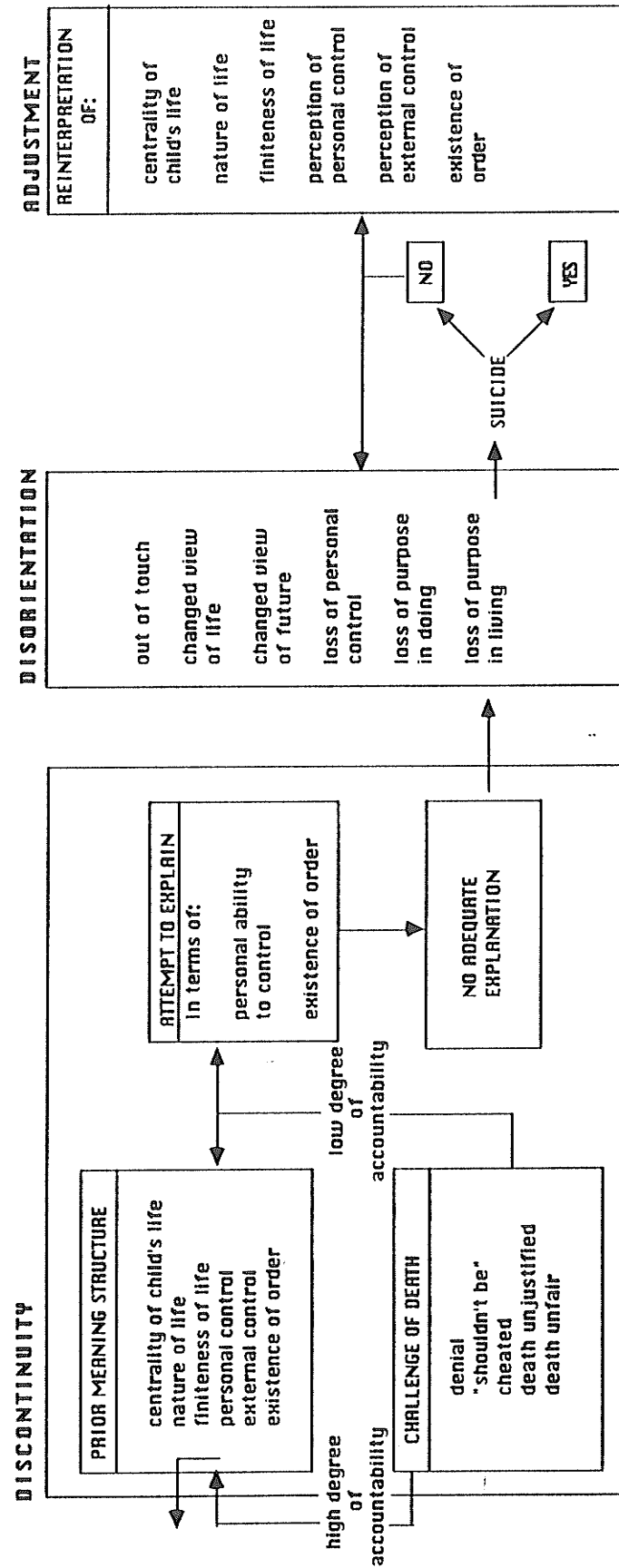
The nature of individual parents' meaning structures, at the time of their child's death, was found to be the core category in the data collected. "Prior Meaning Structures" was conceptualized as representing parents' descriptions of their collection of beliefs, assumptions, values, and norms which characterized their

"reality" or their "knowledge" of life prior to or at the time of their child's death. It was found that a person whose reality constructs accounted for an experience such as a child's death did not experience as much "discontinuity", or a threat to their meaning structure, as did those whose constructs did not account for such an event. When a meaning structure did not account for the challenge which the death posed to it, attempts to explain the death were made in terms of the prior reality constructs.

Under the condition that explanations did not "fit" satisfactorily into the existing structure, "disorientation" resulted. Disorientation refers to the dismantlement of existing beliefs, assumptions, values, and norms. In essence, Disorientation is a conceptualization of the world-shattering experience.

As the only alternative to suicide, in the most extreme case of disorientation, re-orientation follows. Adjustments are made to the prior meaning structure in order to account for the fact of the child's death and to restore the bereaved with a sense of meaning and purpose in life. Adjustment is not necessarily constant. The bereaved person may move back and forth between disorientation and adjustment. Figure 1 illustrates the overview of the theoretical scheme, which will be explained throughout the Findings section.

FIGURE 1. OVERVIEW OF THEORETICAL SCHEME





### The Key Category of Discontinuity

The category of Discontinuity includes the core variable of Prior Meaning Structures and the sub-categories of The Challenge of the Death, and Attempting to Explain. These are inter-linked. The event of the death challenges the prior meaning structure which results in a "fit" or a "non-fit" in terms of whether or not the death can be accounted for in terms of pre-existent meaning structures. Attempts to explain are the resulting response to a "non-fit" of death, when the prior meaning structure is threatened. This has been conceptualized as the phase of Discontinuity.

#### The Core Variable: Prior Meaning Structures

Through the process of analyzing and sorting the data, it was discovered that all of the informants directly or indirectly referred to beliefs, assumptions, values, and/or norms which characterized their life prior to and at the time of their child's death. All references made to this were grouped together and were sorted in terms of properties, that is, characteristics or attributes of the category, Prior Meaning Structures. Each of the properties was dimensionalized (variations were viewed in terms of their placement along a continuum) to account for each informant's story. This is the procedure suggested by Strauss and Corbin (1990).

#### The Property: Centrality of The Child's Life

One of the identified properties includes the place which the deceased child's life held in the parents' sense of meaning and purpose in life. This does not necessarily refer to a situation

where the child provides the parent with her only source of meaning and purpose in life. Rather, it encompasses the notion that the child's life is essential for the parent to derive meaning and purpose from other relationships, pursuits, and activities.

Informants repeatedly referred to their endeavors prior to the child's death as revolving around the life or lives of their child(ren). For example, one mother spoke of having given up a "good job with beautiful benefits" to stay home and care for her children. Working and saving up money to buy a home, a pool, a trip, attending and volunteering at school functions, driving the children to practices and games, investing money toward their education, and so forth, reflect the important role that children play as objects of their parents' purposeful activities.

Another mother (Inf. 2) described herself as having acted as both mother and father to her deceased child, as a consequence of having been married to an alcoholic husband who provided her with little support. She described her strength as being found in the desire to help and protect her son to the best of her ability.

This property also refers to the child's life as being central to the parents' experience of "self", where the child is viewed by the parent as an extension of herself. Closely related to this concept is the view that parents have of their children as being central to their visions of their own futures. One informant stated,

... it's something you don't know until  
you do have kids -- that bond is so  
strong. They're your future. I guess

it's the fact that it's a part of you too, that certainly dies. You're not the same person anymore (Inf. 5, lines [11.] 498-502).

Another informant described her deceased son as having been a bright student, very sociable with other students, musical, comical, and cheerful. In short, as she stated,

I guess he was the one I sort of had all my hopes in, you know? (Inf. 7, ll. 463-464).

On the other end of the continuum, the dimension of the property of the centrality of the child's life, is the view of the child as being part of a multi-faceted meaning structure. As expressed in the story of one informant, her own life was viewed as one for which God had purpose. The place that her children had in her life was "God-given". It follows then that the cessation of one child's life was viewed as part of the entire purpose which was designed for her. In her words:

I still had two healthy children at home. It [suicide] never crossed my mind. That's an easy way out of life, you know -- I have a problem I'll kill myself. That's not the answer. That's not the answer that God wants you to choose. He wants you to keep on living -- he probably wants you to help other parents who have lost children (Inf. 9, ll. 330-339).

#### The Property: Nature of Life

A second property of the category, Prior Meaning Structures, is parents' general beliefs or assumptions about the experience of life as ranging between the view that it is basically good and the view that it is something that presents people with great struggles and

difficulties. Many informants described their lives before the death as being essentially "good" in nature.

I was very fortunate. I had a very secure marriage. I grew up in this part of town, so did my husband. We had long-time friends, no financial problems ... we were pretty content with things (Inf. 1, ll. 18-22).

For me, up until C. died, life was great. I enjoyed everything. I had a good marriage, and good kids. I was very proud of them. We had a lot of fun together (Inf. 3, ll. 201-203).

I had a good marriage, I had a little boy, and a little girl, no financial worries. Life was very good to me (Inf. 5, ll. 152-154).

...we were at that sort of stage when life was going really well for us. The kids were growing up -- one daughter was married, one in university, T. was in high school ... Things were going very well (Inf. 8, ll. 69-72).

On the other end of the continuum are references of informants' experiences, prior to the death, which recognize the more difficult nature of life. One informant described how her profession as a nurse caused her to deal more with life and death than the average person. As she stated,

You deal more with life and death -- more than an average person does. It's a reality that people die. Some people have never even seen a dead person, or known anybody that died ... I work on maternity. I know babies die ... You just know that they do, it's not a big surprise. (Inf. 6, ll. 385-395).

This same informant had also suffered the loss of her husband years ago.

Another informant referred to her own past as being one which was characterized by abuse, which made life so difficult for her that she had contemplated suicide as an escape from it. An experience such as this undoubtedly shapes different assumptions about life than those which are held by someone who has not experienced life as being difficult in nature.

Another aspect which is closely related to assumptions about the nature of life, is the belief people have about their own degree of immunity to tragedy. Numerous references were made to prior beliefs that although they had knowledge that tragic events occurred, they considered themselves to be immune. As Informant #1 stated,

We all know that these horrible things happen, but you never expect that it will happen to you (11. 192-194).

Another informant referred to the confusion she experienced when planning for her daughter's funeral. As she stated,

We had to make these decisions that we never thought -- you never think that you're going to have to make these decisions (Inf. 8, 11. 96-98).

Even when there is an awareness of the possibility of impending tragedy, there seems to be a tendency for people to avoid the consideration of it. As one mother stated,

... when she was a wee baby, and she was in her room, I always felt: I'm going to open the door and find her dead. It was such an awful feeling ... I thought that. Of course I'd quickly shut it out of my mind (Inf. 5, 11. 377-381).

Another mother whose son had had a number of heart defects as a child, stated that she had not thought that he would live a long life, because of his heart. She had expected that he might live until he was in his forties. However, as she stated,

I just hoped I'd be dead before that happened (Inf. 7, ll. 232-233).

Represented on the opposite end of the perceived immunity continuum, is the conscious awareness that tragedies do happen and no one can consider themselves protected or sheltered from the possibility of being affected. As Informant #9 stated,

... there's nothing that's guaranteed (ll. 224-225).

#### The Property: Finiteness of Life

Another characteristic of parents' prior meaning structures includes their prior beliefs or assumptions about the finiteness of life. People may believe that life itself exists only from the point of conception or birth until death or they may view the life span as being part of a continuing existence, for example in the form of a reincarnated person or as the soul continuing its existence in heaven or in the universe. Parents represented these variations in their beliefs and views, with some stating that prior to the death, the question had not been given much thought.

#### The Property: Personal Control

A fourth property of Prior Meaning Structures is the perceived degree of control which parents believed themselves to have in terms of affecting conditions in their own or others' lives. On the one

end of the continuum is the belief that personal or internal power to control outcomes is available. An underlying assumption of this belief is that actions have consequences. Following that assumption is the belief that when certain actions or measures are taken, corresponding results are expected.

Several mothers referred to having had the belief that they had the ability to control aspects of their lives. One informant described herself as being

the type of person ... you have a  
problem, do something about it (Inf. 1,  
ll. 182-183).

In her view, events were determined to a large degree by her response to situations. She also stated that she had assumed that if she "did things right" (i.e., stayed home with her children to look after them, used common sense, acted sensibly), the results would be as they "should" be. Another informant stated,

I always thought that if you lived life  
properly, never hurt anyone else, that  
things would work out (Inf. 3, ll. 180-  
181).

Related to the degree of parents' perceived control over life events, is their sense of responsibility as caregivers and protectors of their children. As one informant explained, although she was not responsible for having caused her daughter's death, she still felt great despair in the knowledge that at one point she as a parent was not able to protect or save her child (Inf. 8).

The opposite dimension of this property is represented by parents' views of themselves as having a relative lack of control in terms of determining events. As one informant stated,

I always thought: what's the point of not doing something you want to do just because you're afraid something might happen to you? If it's going to happen, it'll happen, wherever you are (Inf. 6, 11. 362-365).

Another mother firmly expressed her view that she did not have the power to make decisions in order to control the outcome of situations. As she explained, it's not "up to us" to decide whether or not one's child should stay alive.

...it's okay that you don't control things. I wouldn't want to. I wouldn't want to control, you know? That's pretty scary. I think it's right that we don't control. I don't think anybody should have the power to do that but God (Inf. 9, 11. 409-413).

#### The Property: External Control

A fifth property of parents' prior meaning structures is parents' beliefs and/or assumptions about the existence of external control. This represents references made to a belief in a "God," a "greater being," or a "greater power" who/which determines the course of one's life. These beliefs are characterized by the perceived amount and type of power the external source of control possesses.

On one end of the continuum is the belief that "God" is all-powerful, and that he uses his power for what the parent perceives as "good" purposes. The statement "I really felt that he (God) should have intervened" (Inf. 1, 11. 402-403) implies that this



parent had perceived God as having the power to be able to intervene and that doing so would have demonstrated his use of that power toward a good purpose (i.e., healing her child or saving him from death).

Another informant described her belief in God as having the assurance that he controls everything. She believed that his decisions are always the "best", despite the fact that they may be difficult to accept. Alternately, some parents expressed a disbelief in the existence of an external power source which influences or determines the outcomes of events. Others expressed having had uncertainty in this regard or as never having considered the matter.

#### The Property: Existence of Order

The final property discovered as characteristic of the category, Prior Meaning Structures, includes parents' beliefs and/or assumptions about the existence of order in society, in the world, and/or in the universe. Variation was found in terms of the degree to which these assumptions were held. On one end of the dimension is a belief that basically the world is a place of order, where "taken for granted" or "natural" laws apply. An important aspect of this orientation is the belief that fairness and/or justice exist. This includes views that parents had about people's fortunes being determined by their actions and the idea that somehow people get what they deserve. In the social world, the justice system provides a form of "back-up" to ensure that fairness exists when the world fails to operate as it "should".

Related to people's belief in fairness, is their view of the world as being organized in such a way that their well-being, including safety and security, are ensured. This was demonstrated in the example of one parent's prior trust in the medical establishment as operating to ensure that the best care was given to her daughter (Inf. 5).

Another aspect of assumptions of order is the view people have regarding the appropriateness of death, in terms of the place it holds within the "natural order of things". For example, death is more acceptable for an old person, a sick person, or a "bad" person.

The other dimension of the "order" property, is the belief that another system of order exists, which transcends the view of order which is created by humans. This type of belief is characterized by the view that events occur for a purpose and follow a "greater order" despite the apparent "wrongness" of the event in terms of our society's members' views. As Informant #9 explained,

I do believe [God] controls everything.  
If it's meant to happen, it's meant to  
happen. There's a reason for everything  
... He did this for a reason, and you  
have to accept that (11. 203-229).

#### The Sub-Category: The Challenge of the Child's Death

In the major category of Discontinuity, prior meaning structures were found to have a conditional relationship to the sub-category: The challenge of the child's death. The nature of prior meaning structures is related to the degree to which the impact of the child's death is accounted for. In other words, prior meaning

structures differ in terms of how sufficiently parents can use them to explain or "place" the death of their child.

On the one end of the continuum is a meaning structure which does not account for the child's death. This is typified as one in which the child is central in providing the parent with a sense of meaning and purpose, the child is viewed as an extension of the parent's self, and her future. Also, the nature of life is typically viewed as being basically "good" and a perception of immunity to tragedy exists.

A non-death accounting meaning structure is also characterized by a finite view of life, where life is viewed as not existing outside of the realm of the life-span. A child's death is also not accounted for in a meaning structure which views the occurrence or outcomes of events as being controllable by one's own actions.

A belief in a greater power which acts to serve the same purposes as those desired by the parents also does not account for an undesired death. Finally, a view of society and the world as operating by a set of laws which ensure fairness and order as defined by the parent is presented with a greater threat when the death is viewed as a violation of those "natural" laws.

When the death occurs, parents whose meaning structures did not account for the death, reported feeling a sense of shock, denial, and/or disbelief upon hearing the news. According to Pincus (1974), many bereaved people experience shock in that they are unable to comprehend or "take in" the reality of the death. Shock has also been explained as a reaction which protects the psyche from being

overwhelmed to the point of destruction (Lifton, 1979). It is also possible that this initial response serves to protect the parent from the threat which the occurrence of the death imposes on a meaning structure which does not account for it. The following examples illustrate this notion.

One mother whose child had died during the process of birth, described her response to the nurse who informed her of her child's death:

I said, "no, she's not my baby" ... I kept saying, "it's okay, it's fine, she's not mine. My baby's okay". It was like I really didn't believe it. I thought, you've got the wrong lady, maybe the woman in the bed next to me, it's got to be hers (Inf. 4, ll 29-42).

Upon receiving the news that her son had been discovered dead, another mother recalled,

I was really in a daze, crying of course -- just absolutely could not believe it. I thought it was a dream, it wasn't really happening (Inf. 7, ll. 27-29).

Another woman who was out of the country at the time when she was informed of her daughter's death stated that her immediate thought was:

This is a big mistake, when I get back home I'm going to sort all this mess out (Inf. 8, ll. 79-80).

A major theme which emerged from the analytic process was that the child's death presents a threat to parents' prior views about the existence of order, including their notions about the way life "should" be. The following examples refer to the death as an event

which caused parents to view life as having become something other than what it "should" have been.

We used to go out for dinner quite often and four chairs would be filled. Sometimes we go out and if E.'s [other son] girlfriend doesn't come with us, we have an empty chair. I far prefer when she comes because then we have four chairs filled. Even sitting in our dining room here, only three chairs are filled. It just seems so unfair (Inf. 3, ll. 187-192).

I quit my job when I was pregnant. So all of a sudden, I'm home, I have nothing to do. The nursery was still set up (Inf. 4, ll. 109-111).

... The days were so long. With a newborn you're so busy. There's so much to do. All of a sudden I had all this time on my hands (Inf. 5, ll. 686-688).

You know, her birthday's coming up, and all those days are so important, Mother's Day, Christmas ... All those special holidays. There's always that missing person (Inf. 5, ll. 119-122).

Sunday supper was always the time when my oldest daughter came out -- she had a little girl. And it was awful. I couldn't sit down at the table. It didn't matter where I sat, there was always an empty chair. It was terrible (Inf. 8, ll. 221-225).

Whatever you do, there's always ... you realize this is not quite the way it should have been. But my daughters, at our wedding anniversary thought we should have a family portrait. I kept saying: "no, no, no, no way". Because my feeling is now we can't have a family portrait. You can't have a family portrait when one member is not there (Inf. 8, ll. 411-416).

It's the physical sense that he's not here and I'm not supposed to be looking for a job. I'm supposed to be staying at home taking care of the child ... when you leave the hospital you go in for a

pregnancy, you're supposed to come out with a baby, right? (Inf. 10, ll. 29-39)

Frequent reference was also made to the fact that parents felt they had been cheated by the death of their child. The following excerpts illustrate this.

I'd give anything to have a grandchild from C. Without that I feel cheated. All those years of watching him planning and looking forward to when he gets married and has his own family ... (Inf. 3, ll. 211-215).

It leaves such a hole in your life and you feel so much as if you've been cheated. We've had five kids come along in the family and I look at them all and I say to myself: I wonder what T.'s children would have been like (Inf. 8, ll. 460-463).

It's just a sense of being cheated, like robbed. You want this baby and now you don't have it (Inf. 10, ll. 151-152).

The threat of the death to parents' assumptions about the existence of order is also demonstrated in terms of the views parents held regarding the circumstances under which death is expected, appropriate, or justified.

Informant #2 described her thoughts while working as a nurse for elderly patients,

I couldn't equate the whole thing. It just seemed so bizarre that young people would die, and these poor old people go on and on and on. I found it very depressing (ll. 264-207).

Informant #8 stated,

I found I was able to cope with the death of my father. These are things you know are going to happen one day. Although it's very sad and very upsetting, you are prepared for it. However sad it is, you know it's going to happen. What we

couldn't cope with was that we lost one of our children (Inf. 8, ll. 38-43).

A child's death also threatens parents' beliefs and assumptions about the existence of fairness and justice. Several excerpts which were categorized as concepts relating to the child's death as being viewed as undeserved or unfair illustrate the threat which the loss posed on those prior assumptions.

So you stay home with your children, you don't let them go out at night, you drive them here, and you take them there, and you look after them, and do everything to the best of your ability ... and my son dies!!! (Inf. 1, ll. 188-191).

Later in the interview, this same informant referred to a letter she had received from a local church:

Something was said about us owing God for our health and good fortune. I felt like saying, "Then I deserve a refund!" (Inf. 1, ll. 434-436).

Other informants stated,

I think I could have accepted his death a lot better if it had been his heart. It turned out to be something totally different, and so rare. It seemed so cruel. As a little boy he'd suffered so much (ll. 77-80) ... It seemed so unfair for him to get something else like this ... I do know that I have felt much more bitter that he should get that [virus] because he'd been born with a heart that wasn't right. Then he'd suffered and gone through so much and had been such a brave boy through it all, and then to have life taken from him by an extremely rare thing. It just seemed so cruel (Inf. 2, ll. 162-172).

This is a terrible thing to say, but these people that are on drugs, and killing other people ... why not them? I think of some of these characters, and they'll probably go on living until they're 90 (Inf.3, ll. 196-199).

This isn't very nice, but this is the way I thought: You know, you see the native women and they're pregnant and they're drunk. Why not do it to them? Or these women that want to have abortions. Why not make it happen to them? But not to me. My husband and I, it took us almost a year to have M. And we were so excited, I was so angry that it was me (Inf. 4, ll. 192-198).

You look around, I still do ... You go down Main Street and see all these bums. I feel really angry. All these good kids that die, and all these useless people out here. That's not very nice, but that's the way it is -- useless bums that are just a plight on society. Who knows how they got there. But you resent the fact that all these other people are still alive ... (Inf. 6, ll. 185-192).

You know you're a good mother. Why do all these people that smoke cocaine have babies? And then these babies have to grow up like that, and yours was taken from you (Inf. 10, ll. 152-155).

#### Factors Contributing to Non-Death Accounting Meaning Structures

As was discussed previously in the section on Phenomenological Theory, according to Berger and Luckmann (1966), meanings of individuals correspond with those of others. Through the process of interaction, commonly shared views, beliefs, values, and norms become characteristics of a society or culture. Many of the shared meanings among members of our society do not provide acknowledgement of the possibility of child death, nor do they provide explanations which account for such an event.

#### Societal Valuation of Children

Our present-day culture is characterized as one which places great value on the lives of individual children. According to Aries (1962) this has not always been true of Western civilization. In



fact, up until the beginning of the modern era, children were viewed as relatively unimportant in family and social affairs and were often neglected. Their value was typically limited to the amount of labor they contributed.

Children in our modern society no longer provide economic benefits to their parents as they once did or as they still may in other cultures. In fact, parenting a child in our society requires a significant financial investment for which there is typically little economic return. However, the vast majority of married couples in North America still desire to have children. Although the birth rate has been declining, the percentage of parents desiring at least one child has not declined (Garrett, 1982).

In addition, the availability of safe and effective contraception has allowed couples to plan for their pregnancies. This implies that increasing numbers of parents have children whom they want and for whom they have prepared -- often in terms of having met their own educational or financial goals.

In sum, parenthood in our modern society has increasingly become typified as a planned for, personal and emotional investment in the lives of only a few, or even just one child. This may help to explain why children are so central in providing meaning in the lives of many Western parents and why the death of a child presents them with such a threat.

As Folta and Deck (1988) speculated, little has been reported about parents' reactions to child loss in countries where infant mortality is an expected and frequent occurrence, because it is

assumed that it is not experienced as a crisis. These researchers, who interviewed bereaved mothers in Zimbabwe, discovered that this assumption was incorrect.

They found that women expressed feeling a deep sense of loss and sadness from the loss of their child. Women who had experienced several losses described no less sadness than did those who experienced only one loss. Although their findings suggest that child loss is also experienced as difficult by mothers in non-Western cultures, future research may focus on whether or not there are cultural differences in terms of how parents accept or explain the loss.

Another issue for consideration is whether or not parents of an only child are more prone to viewing their child as central to their sense of meaning in life and therefore are more threatened by the child's death. In the present sample, two of the four mothers whose deceased son or daughter had been an only child, described their experience as being worse because of that fact. Other parents commented on the fact that they would have perceived the loss of their child as being much worse had they not had other children.

As was discussed previously, a greater percentage of parents are choosing to have fewer children. If the presence of fewer children is related to a higher degree of their centrality in their parents' sense of meaning in life, then increasing numbers of parents may be more profoundly threatened by a child's death. It is also possible that the threat of an only child's death on the parent may be intensified when the parents' child-bearing years have been

outlived. The population at special risk of the threat of child death may be the increasing numbers of parents who choose to delay childbirth, thus limiting the possibility of future pregnancies and who have an only child.

#### Shared Meanings of the Nature of Life

The beliefs and assumptions our society's members have about the basic nature of life represent a second area of factors which contribute to the formation of meaning structures which do not accommodate child death. The notion of the "American Dream" is that success in life can be achieved and that life "should" be basically good. As Informant #5 from the present sample stated,

I think you're led to believe that life  
is going to be wonderful and it's not ...  
we do believe that life is going to be  
just great. We're under that illusion  
(11. 410-415).

In fact, most of our endeavors revolve around the improvement of the quality of life for ourselves and for those we love. As Informant #2 stated,

If you're a parent, all you really want  
for your child is a life -- a happy life  
(11. 92-93).

People who take on hardship or deny themselves pleasures of life for whatever reasons, such as martyrs, are generally viewed by Westerners as being eccentric and out of the realm of what is considered "normal". What is considered to be "normal" is the pursuit of happiness in life. The expectation of life to be "good" does not account for suffering.

In other words, when people are confronted with a situation which causes them to suffer, that situation is viewed as something that has gone wrong: "life should not be that way". The consequence of these beliefs and assumptions is that the incidence of crisis is not accounted for, including the event of a child's death.

#### Societal View of Life as Limited to the Life Span

Some members of our society also place emphasis on "life" as being the experience from the time of conception or birth to death. The term "life" has meaning only when it is viewed in the context of its existence on earth. In our technological society, an objective reality consists of only those experiences which occur in the natural world. Therefore, references to the existence of an after-life, or the possibility of reincarnation typically are not considered seriously as reality.

The implication of this is that we expect all of life's "real" meaning to be realized in the course of the life span. It makes sense to us that an old person who has "lived a full life" dies, but it does not make sense that a child who has not even begun to truly experience life should die.

#### Societal View of Self as Determiner of Outcomes

A fourth contributing factor to non-death accounting meaning structures is the characteristic of our society as being one in which members typically view themselves as determiners of their own success or failure in life. Hiebert (1983) described the American world-view as being achievement-oriented. Hard work, careful planning, and the efficient use of time and money are expected to

ensure success. Ultimately, the individual is viewed as responsible for his or her own success or failure.

The world is viewed as predictable in that certain actions are expected to yield corresponding consequences. Although not all disasters such as accidents, illness, or death can be prevented, extreme measures are often taken to minimize their incidence or the effects of them. A basic orientation characteristic of North Americans nevertheless, is a belief that if life is lived "correctly," then desirable outcomes are expected. For example, parents read manuals which teach them to raise well behaved children, people educate themselves to prepare for the job market, they save money for retirement, and delay marriage and the births of their children to ensure that certain personal or financial goals have been met.

This type of orientation in the world is one which is threatened when parents who believed that they were following all of the appropriate "rules for success" discover that the event of a child's death cannot be explained. Parents who viewed themselves as having lived life properly, having done everything to the best of their ability, find that their prior views of themselves as able to control things are called into question.

#### Societal Denial of Death

A final factor to be discussed in this section, is the manner in which the general denial of death which characterizes our culture contributes to meaning structures which do not account for a child's death. In a discussion of modern attitudes toward death, Aries

(1975) explained that talking about death, thereby admitting it as a normal aspect of life, is no longer acceptable in our society. The mere mention of the term "death" arouses tension which disrupts the routine of life. Even an incurable disease such as cancer is not equated with death, since partial recovery is possible, allowing the diseased person to expect many more years of life.

In addition, the event of death itself has been removed from the setting of the home and placed in the hospital. As Kubler-Ross (1969) explained, this illustrates our increasing inability to prepare ourselves and our families to acknowledge the reality of death and face it calmly. Instead of allowing people to die peacefully in the comfort of their own homes, they are rushed to emergency rooms where medicine and technology are designed to prevent or postpone the death.

In our society, denial of death is learned at a young age. Children soon learn from adults that the subject of death is taboo. The word death is viewed almost as a "dirty" word (Grollman, 1986). Often, when a loved one dies, adults give misleading information in an attempt to "cover up" the reality of the death. For example, children are told that the deceased person "went on a long journey".

Often children are also removed from the situation where the death occurred, or are not permitted to attend the funeral of the deceased person. As Kubler-Ross (1969) noted, the child senses that something is wrong. When adults avoid the child's questions or offer misleading explanations, a sense of fright and mystery surrounds the subject of death.

In a society where the reality of imminent death even for terminally ill and old persons is denied or removed from the everyday routines of living, consideration of the death of a child seems an obscenity (Yudkin, 1968). This is especially true because children who are born in the modern Western world are almost certain to survive. Discussion about the possibility of child death may be viewed as representing the epitome of taboo subjects in our society.

Many other types of crisis or difficult experiences are recognized as normal possibilities in life. Some examples are unemployment, financial ruin, marriage break-up, illness, and deaths of aged friends or relatives.

In fact, many people make plans or prepare themselves in various ways to deal with those types of risks of living. For example, women may make arrangements to ensure their own financial security in anticipation of later widowhood. Money may be invested for security in the event that a job is lost. Children may spend more time with their aging parents, knowing that their time together is limited. Or, couples may form pre-nuptial agreements in recognition of the possibility of a future break-up of their marriage. On the other hand, the possibility of a child's death is most certainly not a subject which people talk about, much less prepare for.

The effect of a society characterized by these attitudes which people have about child death is that parents within that society who lose a child are unable to account for that death in terms of

their existing meaning structures -- meanings which were previously shared with other members of that society.

A common response of others to bereaved parents is to ignore the topic of the child's death, thereby demonstrating a continued denial of that reality. As one informant stated,

... nobody talked about T. Nobody even mentioned her. You wouldn't have thought that we'd had this horrendous thing that we thought had happened to us. We were there, were dragging ourselves around and yet whenever we went to visit any member of the family, everybody very carefully avoided mentioning T. They'd ask about the other girls, ask about our granddaughter. They never mentioned T. (Inf. 8, ll. 248-254).

Although this type of response may be intended to avoid upsetting the bereaved person, the underlying message is one which denies the fact that life for that person can no longer continue as it did before the death.

Whereas societal denial of death may protect many people's illusions that death will not affect them, the experience of child loss for parents who shared those illusions is intensified, in the sense that they have no way of accounting for that death. In addition, they are also deprived of the support from others who acknowledge the reality of the death and its impact on the bereaved parent.

#### Summary

In sum, our society is characterized by members sharing a constructed reality in which the following are considered to be "true": individual lives of children and the parenting of them



provides meaning and purpose in life, the nature of life is basically good, life does not have meaning outside of the realm of its existence from conception until death, personal control determines the outcome of events, order exists in the world, and death does not exist.

As Berger and Luckmann (1966) elucidated, there is a certain degree of danger inherent in the constructed realities of humans, in the sense that the reality constructs are in constant threat of collapse. For example, children do die, life is not always good, not everyone lives through the life span to reach old age, things happen which are beyond our control, doctors make mistakes, laws do not always protect people from harm, and death can strike any one at any time.

#### The Sub-Category: Attempting to Explain the Death

Another sub-category of the major category, Discontinuity, is parents' attempts to explain their child's death. This sub-category was found to co-exist when the challenge of the death could not be accounted for by the parents' prior meaning structures. In essence, by asking "why?", "why me?", "why my child?", parents were attempting to make sense of the death in terms of existing meaning structures which held no "place" for the possibility of such an event.

The frequency of parents' reports of asking "why?" parallels the findings of Sanders (1980) who reported that among the fourteen bereaved parents who participated in her study, there was a general pattern of attempting to explain the mystery surrounding their

child's death. Parents seemed to need some missing explanation to put the event in perspective. The discovered relationship in this study, of attempting to explain "why?" because of a lack of fit with prior meaning structures, may help to explain why parents are asking "why?".

In the case of the informant who expressed complete and immediate acceptance of her son's death, the challenge of the death did not pose a threat on her existing meaning structure, because it accounted for the death. In other words, she could explain the death and make sense of it. As she stated,

I'm a very religious person and I do believe that what God did was the best decision. He would have suffered all of his life. He would have had to have surgery after surgery after surgery. So He [God] took him right away instead of making him suffer more, because he suffered all his life already -- four months and he suffered the whole four months (Inf. 9, ll. 146-152).

Later in the interview she stated,

I know there's a reason for it. I don't think I'm searching for it. I just accept it. I think that's what you have to do if you want to get on with your life (ll. 455-457).

An existing meaning structure which was characterized by a belief in a God who controls events of life and makes decisions based on the serving of good purposes, sustained the impact of the threat which the death posed.

Attempting to find explanations that "fit" their prior understanding of life, was described as being much more difficult for the other informants in the study. Each of those mothers

described themselves as having grappled or as still grappling with the question of why the death happened. This is illustrated in the following excerpts:

Why me: Why not another woman who was having her baby at the same time? Why couldn't it have been her? I couldn't figure it out (Inf. 4, ll. 177-179).

The odd time I'd be sitting there and another boy would go by, and I'd look at him and think: Why wasn't it him instead of C.? And it just didn't make any sense that it had happened to C. And I don't think it makes a lot of sense now (Inf. 7, 93-99).

Through the process of scrutinizing the stories of the informants, it was found that among those parents to whom the death posed a threat to their existing meaning structure, an attempt was made to explain the death in terms of their existing understanding or "knowledge" of their ability to control the outcomes of events and the existence of order.

#### The Property: Ability to Control

What characterized parents' attempts to explain the death in terms of their view of being able to control life events, was their belief that there are things that could have or should have been done to prevent the child's death. Parents who held this belief also expressed feelings of guilt because they had not prevented the death or because they felt responsible for it. As informant #3 stated,

I have felt a lot of guilt about his death, wondering if I could have prevented it from happening (ll. 5-7).

In the attempt to assess their own responsibility for the death, parents often searched diligently for what it was that they had done "wrong". Some examples follow.

You constantly say "why" and "if". I often feel that if I hadn't come here, if I'd stayed in England, perhaps this wouldn't have happened ... I know it wouldn't have made a difference, wherever we would have been, it's just maybe he wouldn't have got it [the fatal virus] if we wouldn't have been here. But you always do that. You always say if ... if we would have taken him to England with us he wouldn't have gotten it. You torment yourself with those kinds of things (Inf. 2, ll. 377-391).

One informant whose daughter died because of an adverse reaction to immunization stated,

There's a lot of guilt too, because I trained as a nurse and was working as a nurse when L. was born. In my training I'd never been taught anything about adverse reactions. I believed it was totally safe. I felt being in a medical profession I should have known. I felt I was too trusting of the doctors. I should have investigated more on my own ... So I felt guilty that why did I wait two and a half months after this [symptoms of the reaction] happened? Why didn't I take her to Sick Kids right away? ... I thought if I had taken her right away they would have picked it up, and she never would have been immunized with the second needle (Inf. 5, ll. 221-253).

Another aspect of some parents' search for what they could have done "wrong" involved looking back into their own past in an attempt to discover what it was that they had done, that deserved this punishment. As informant #4 stated,

You start thinking what have I done?  
It's got to be my fault. I started thinking back about all the things that

have happened in my life. Maybe I'm getting punished for something I did when I was a kid (11. 226-230).

Informant #8 stated,

I went through a long time thinking: What did I do? Why should God punish me like this? What did I do that was so bad, that God had to punish me by taking my daughter? (11. 689-692)

Another informant described how she had asked herself:

Why were we the chosen ones to have Him, when I speak of Him I mean God, why did he take our baby? We just lived together so I thought maybe it was that ... (11. 103-106)... And then I thought, at that time we weren't living together, so I thought maybe having premarital sex before marriage ... I thought maybe it was that. I was grasping at straws, looking for an answer (Inf. 10, 11. 431-434).

#### The Property: Existence of order

In a meaning structure which assumes the existence of order, there is a belief that other people behave in such a way that order is maintained. When a child's death threatens that assumption, parents may attempt to explain the event by attributing responsibility to others for what they should have or could have done to prevent the death from occurring.

Informant #7, whose son had been hit by a truck and killed as he was walking home from a social event, expressed how she had blamed her husband for her son's death:

G. was here when T. [son] phoned. If he'd heard me offering T. a ride home, he would have got ticked off ... "The kid's supposed to be on his own and you shouldn't be catering to him" (11. 208-211).

This informant described how her knowledge of her husband's probable disapproval had prevented her from offering her son a ride. In her view, this had resulted in her son's death.

Informant #8 described how she had attributed responsibility to others for her daughter's death. Her death was caused by a drunk driver in a car accident. According to this informant, the justice system should have been more stringent in the enforcement of laws prohibiting people to drive while drunk. Also, the people in the pub with whom the driver had been drinking, as well as the person(s) who had been serving him drinks should have prevented him from driving.

Another aspect of assumptions about the existence of order in the world and/or in the universe, is that there are reasons for why things happen. For example, bad things happen when people deserve to be punished, they die because they are ill, or because they are old. Many parents attempted to understand their child's death from the perspective that there should be some reason for its occurrence that would make sense of it.

Informant #1 for example, described herself and her husband as decent, honest people who worked hard for what they had and who were appreciative of it. Her belief was that she had been a good person and did not need to lose her child to become a better person, or to learn to appreciate what she had. In her view, the death served no purpose that she could understand. The implication of her statement is that the death would have made some sense if there had been a lesson that needed to be learned.

Other informants commented on the fact that they could not understand why their child had died, because there had been nothing "wrong" that would have warranted the death as being acceptable. As Informant #2 stated,

The doctors said there was no reason why he wouldn't live to a good old age, and live a normal life. After 17 years after the surgery, you think everything's alright ... For something to happen so quickly. I think too, that if you ever have a child who has been ill you could comfort yourself in that they've been released from pain. He didn't have that (ll. 84-90).

When comparing her late husband's death to her son's death, Informant #6 stated,

Here was this guy who was 220 pounds, down to about 140. You know, I knew he was suffering. Whereas T., he was perfectly healthy. There was no reason for it (ll. 583-585).

As Informant #7 stated,

I can't think about him walking down the street and suddenly falling and dying like that. He was never sick before. There was nothing wrong with him in connection with his heart from the day of his surgery. There was no reason to imagine that anything was wrong, you know? (ll. 330-334)

The child's death was also viewed by some as being unwarranted because they could see no "good" in the death. In other words, the death would have been viewed as more acceptable if it would have "fit" their assumptions of order: things happen for good reasons. For example,

I would have felt better if they'd been able to isolate a virus from his death so that perhaps someone else might not die.

That would make me feel better. But they weren't able to do that ... (Inf. 2, ll. 394-397).

As Informant #8 stated,

Although Citizens Against Drunk Driving was very much in memory of T. and her friends, I don't go along with people who say, "well you've made something worthwhile out of her death". I would much rather be able to turn the clock back (ll. 380-383).

In parents' attempts to explain the death, it was discovered that explanations or meanings which were offered by others were negatively reacted to when those explanations did not correspond with parents' prior meaning structures. This sheds some additional light on the nature of meaning structures as being resistant to incongruent information.

As one informant recalled, a girlfriend had told her that it was better that her child had died as a baby (rather than as a grown child). The mother's reaction to this comment was:

I thought, one more person says that and I'm going to explode. I'm just going to explode! If I hear one more person say "God had a reason", I'm going to scream. You want to know then, what's the reason?!! (Inf. 4, ll. 251-252).

Another informant described how people had told her that it was better that her baby had died, because his disease would have caused him to be disfigured or handicapped. This explanation was unacceptable to the mother, because as she explained, it was her child and she would have loved him regardless of what he may have looked like. In her view, that was not a "good" reason for his death (Inf. 10).



Despite the attempts of parents to explain or account for the child's death, the underlying theme which emerged was that when their prior meaning structures were characterized by assumptions of having personal ability to control the outcomes of life events and the existence of order in the world, the child's death could not be adequately accounted for. Even when parents attributed responsibility to themselves in terms of what they could or should have done to prevent the death, the realization persisted that the preventability of death was not in their complete control.

As Informant #2 stated,

The only thing that could have saved him was a heart/lung transplant, but he died too quickly (ll. 153-154) ... Now I know about [the] syndrome. I know it wouldn't have made a difference, wherever we would have been (ll. 384-386).

Essentially, parents who existed in a reality in which they perceived themselves as having control, where others did what they "should" do, and where things happened for good reasons, found themselves unable to make sense of the death. Ultimately, they were unable to make sense of their post-death world.

#### The Key Category of Disorientation

The core variable, Prior Meaning Structures, subsumed by the major category, Discontinuity, was found to have a co-variant relationship to the category, Disorientation. Among parents for whom the nature of their prior meaning structure did not account for the challenge which the child's death posed to it and adequate explanations could not be found to make the death "fit" in terms of

their understanding of that reality, the consequence was a high degree of disorientation. The parent for whom the child's death posed little threat to her understanding of reality and who, therefore, did not need to search for explanations to account for that death, experienced a low degree of disorientation.

The category, Disorientation, was conceptualized as the resulting collapse and dismantlement of prior non-death accounting meaning structures. These were characterized by the child's life providing a sense of meaning and purpose in life, an assumption of the nature of life as being good, life having meaning in the context of its existence on earth, a perception of personal power to control life events, an assumption of the existence of an external power source whose use of power corresponds with individual perceptions of what is "good", and an assumption of order existing in the world, where fairness and justice are considered to be taken for granted, natural laws.

Attributes of the major category, Disorientation, were represented by the codes: "out of touch", "changed view of life", "changed view of future", "loss of control", "loss of purpose in doing", and "loss of purpose in living". These properties were found to co-exist as various resulting effects of disorientation.

#### The Property: Out of Touch

When the death of their child could not be accounted for or explained, several parents reported that they felt disconnected from the world. They viewed themselves as no longer existing as part of a world that made sense. The reports of several bereaved parents in

Sanders' (1980) study, who described themselves as moving through an unreal world, are similar to the reported experiences of parents in the present study.

Recalling her feelings shortly after her son's death, Informant #1 stated,

If the world stopped tomorrow I wouldn't care. I don't know how the world can go on. How can the sun shine, and everything go on as though nothing has happened? ... I felt like I wasn't part of the world anymore ... I felt like the world was going by and I wasn't part of it (ll. 905-913).

Another informant stated,

I remember really being surprised that the world kept going on after she died. I mean you'd see neighbors running around outside. I was really shocked. Like, how come everything is going on like normal? It's not normal! Life is not normal anymore! But it does, it goes on, you know? I remember being really shocked, I was really surprised that everything seemed to be carrying on as usual when my whole world was completely falling apart (Inf. 5, ll. 431-445).

Informant #6 stated,

I'd look around and all these people are laughing and you think, how come you're laughing? How can you possibly laugh? Or you look out and people are still out there. How can you be there? How can you get up and go to work? Walk down the street? You can't believe that life goes on (ll. 472-477).

Another aspect of the property, Out of Touch, is the experience which parents described of feeling disconnected from a world in which the normal activities and routines of living had meaning. The following excerpts illustrate this concept:

I went [out with friends], but I wouldn't talk. What did I have to say? "How's the weather? I don't know. I haven't looked outside in days" (Inf. 4, ll. 336-338).

It makes you different from other people. I found I had nothing to say ... I didn't have anything else to talk about (Inf. 7, ll. 525-535).

I was in a different category, the things one would laugh about and discuss didn't mean anything to me (Inf. 1, ll. 52-55).

The effect of lost meaning in the normal activities and routines of life was also reflected in some of the responses of parents toward other peoples' problems. Parents seemed to become more selective in terms of their willingness to offer sympathy. In other words, their own experience of losing a child changed their perception of what deserved sympathy in comparison to that experience. Many of the concerns which other people related to the bereaved parent were viewed as meaningless.

... You are less tolerant of the stupid things that bug people. That really turns me off. I remember the first winter after K. died, we were at a hockey game, and this lady said something about her son failing a Chemistry exam. She was so upset and distraught about this ... I just wanted to say, well maybe if your son had died you wouldn't have had to be so distraught about his Chemistry exam! I thought, how can she stand there and tell me how upset she was about this bloody Chemistry exam when my son has died?! ... Things like that absolutely blow your mind. When there are little things that bother people, they won't get sympathy from me (Inf. 1, ll. 974-989).

I have no feeling for people who are having problems, like when people at work are complaining about what their kids are doing. I just have no patience with that (Inf. 3, ll. 139-141).

I've got a girlfriend that's always complaining about her husband ... well shut up already! Be happy for what you've got. Your kids are healthy ... But you can't say that to people (Inf. 6, ll. 298-301).

#### The Property: Changed View of Life

Another aspect of disorientation is characterized by parents' reports of changes in their views of the nature of life. A view which was once held about life as being secure changed to a view of life as being fragile. This changed view resulted in fear and distrust among many parents.

Similar findings were reported by Dyregrov and Matthiesen (1986) who examined subjectively reported anxiety reactions of 117 parents who had lost an infant. These researchers interpreted parents' reported feelings of insecurity in the world as confirmation that parents who lose their child experience a change in their beliefs about the world as a "safe" place. Several excerpts from the present study illustrate parents' changed life views:

You just realize how fragile life is. That bothers me. It's something hanging over your head (Inf. 1, ll. 1003-1004).

You see life differently. There's no purpose. You're much more prepared for bad things to happen than good. You don't trust life at all, not for you or the people you care for. You're afraid. You look at everything through different eyes, very, very different (Inf. 2, ll. 176-181).

I sort of look at people. I see mothers out here playing with their little kids, 4 or 5 or whatever, and I look at them and think: I wonder if that child is going to be here, you know, when he's 17 or 27? Like, does that mother just

assume he's going to be here like I assumed C. was going to be here? (Inf. 7, ll. 223-228).

#### The Property: Changed View of Future

Closely related to parents' changed view of life, is the incidence of parents' reports of a changed view of the future. Concurrent with a collapse of assumptions about the security of life was a loss of hope for the future.

I don't think I had any hope for the future at all. I felt so desperate. I really didn't feel that I ever would survive. Nothing mattered anymore (Inf. 1, ll. 364-366).

He [deceased son] looked forward to everything, just the way I used to. And now we don't (ll. 155-156) ... I don't any longer look forward to later life, when the children are out of the house, G. [husband] and I being on our own. I don't even think about it anymore. I used to like daydreaming ... thinking about what was going to happen. Now I don't see anything in my future (Inf. 3, ll. 315-320).

#### The Property: Loss of Personal Control

A changed perception of their power to control events was reported by several parents who had previously assumed that consequences could be controlled by their actions. As Informant #1 stated,

After you've done all these things that you think are right, your son dies!! It's like a total lack of control. You've lost control of your life. Nothing matters anymore. It doesn't matter that you've done things correct. It didn't work out that way (ll. 590-603) ... I've come to realize that no matter what you do, the results are never what one would expect. That's the way it is, and it's unfair for a lot of people (ll. 640-642) ... working hard, staying home with my

children didn't guarantee me anything  
(11. 896-897).

Informant #3 stated,

I feel I have no control ... At first I panicked. I really did panic. That's probably one of the reasons why I had trouble sleeping and functioning properly -- because I was really worried (11. 299-302).

The Property: Loss of Purpose in Doing

For many parents, the central place which their deceased child had held in providing them with a sense of meaning and purpose in life before the death, was a condition which caused previously meaningful activities to be perceived as meaningless after the death. As Informant #7 recalled,

I didn't do any cooking or anything like that -- nothing really that I'd done before. I just wasn't interested in doing anything. I can't say I have a great deal of interest in it now ... It seems to me as if there is nothing -- there is no reason to, you know? ... I guess the kids were really what was important to me. So after C. died, my oldest son had left home already, it was just my husband and I, and there seemed to be no point ... I have to get a job. But I don't look forward to it because to me there won't be any reason to do that either. Like C. would have been finished his grade 12 in June and then go to University in the fall. That would have been a reason, you know -- to keep working so he could go to school. And ... but now there just doesn't seem to me that there's a reason (11. 133-169).

As Informant #1 stated,

I remember even just doing the housework. I'd manage the basics. You have to clean the bathrooms, do laundry. Then I'd think I should dust, so I'd dust one or two things downstairs, and I'd think, who cares? I'd go back to the couch. This went on for years (11. 344-349).

Informant #8 explained,

I certainly lost my motivation. I was always very self-motivated. I'd built up what I thought was quite a good business in a very competitive business, in a lousy market at the time. But I lost all my motivation, it didn't seem to matter whether I worked or not (11. 193-198).

#### The Property: Loss of Purpose in Living

The resulting effects of disorientation, or the collapse of prior meaning structures, is manifested in its most intense form in the loss of a purpose in living. The following excerpts illustrate this effect of disorientation.

Sometimes you wouldn't get out of bed, 'cause you thought, what's the point? (Inf. 10, 11. 594-596).

It just seemed to me that when E. died, all my strength went with him. There doesn't seem to be much for me to fight for anymore (11. 137-139) ... There's no purpose (Inf. 2, 11. 176-177).

It doesn't matter about anybody else. I know I've got all these other kids, they're fine, a good marriage, financially stable, no other problems, but you just want to be dead (Inf. 6, 11. 126-129).

It's like I'm wondering why I'm still here, you know? Because there doesn't seem to be a great deal of purpose for me to be here. I don't have children to look after. So there doesn't seem to be a lot of reason (Inf. 7, 11. 153-156).

Most of the nine informants who reported experiencing what was conceptualized as disorientation, reported either a wish for their death or the serious consideration of suicide. This was a consequence of a lost purpose in living. Essentially, the pain of



the loss was experienced as so severe, that life no longer seemed worth living. As Informant #1 stated,

Some people, when they have problems, talk about killing themselves, but I don't joke about that. I truly felt suicidal. I would say that was well after three years. I really didn't think I ever would survive ... I used to say, if K. had to die, I wish we could all die (ll. 141-151).

In her interviews with sixteen bereaved mothers, Edelstein (1984) also reported the frequent incidence of parents' wish to die. According to this researcher, the wish to die represented the parents' wish for renouncement of the burden of living. This was viewed by Edelstein as a symptom of depression. The conceptualization which emerged from the present study, of suicide contemplation as a response to lost meaning, may also explain why the women in her study wanted to renounce the burden of living and why they were depressed.

Among the parents who expressed a consideration of suicide, it was found that what prevented some from following through with that action, was a reported sense of responsibility for other people in their lives. Typically, mothers who had one or more other child(ren), reported that to be the reason for why they did not follow through with the suicide. The following excerpts are illustrations of this.

And sometimes after the three year mark [since the son's death], I thought: if it wasn't for my other son, I wouldn't be here (Inf. 1, ll. 139-141).

I didn't want to live anymore. Again, I thought of my son. I didn't think of my

husband. I just thought, Q. (other child) can't go through this, losing a mother too (Inf. 5, ll. 507-509).

Afterwards [thinking about suicide], you start to think, well you can't put your kids through that (Inf. 6, ll. 144-145).

In the case of another informant, her desire to have other children prevented her from committing suicide.

That's another thing, when I thought I wanted to kill myself. And I'd think: no, I want to have a baby, and I want to have a family (Inf. 4, ll. 312-314).

Other informants reported other relationships with parents, or a brother and sister as the reason for why they did not commit suicide. One informant explained that her fear of the possibility that by committing suicide she would never see God and therefore never see her child again. This was an aspect of the Roman Catholic teaching which she had retained from her childhood. As she explained,

What if that's right? What if that's true and I would never see C.? Okay, I wouldn't be hurting here on earth now, and missing him, but what if there is a chance that I would see him, and if I would commit suicide that chance was gone, you know? (Inf. 7, ll. 704-709).

A finding which emerged from the stories of the women in this study, is that when a person's sense of having a purpose in living is challenged to the point where suicide is seriously contemplated as an escape from a meaningless existence, a sense of responsibility toward other people and relationships with them filter out as being meaningful enough to prevent following through with the suicide. In

other words, relationships with other people were what they described as really "counting" in life.

Although in our society the attainment of material goods, and financial and/or professional success are considered to be important factors in providing meaning to people's lives, none of the mothers in this study reported these as being reasons to go on living. As Informant #4 explained,

Before I had a good job. My husband and I were saving up for this house. We were going to have a perfect family with kids all around -- we were going to have all this stuff. Then when M. died, I thought I didn't care about anything. I didn't care about the money, I didn't care if I ever have a house (ll. 284-289).

Although a sense of responsibility toward other people emerged as the factor which prevented parents from committing suicide, this factor alone did not explain how a meaningful and purposeful life from that point onward was restored. This is relevant considering the fact that many aspects of parents' basic understanding of the world had collapsed. The category, Adjustment, subsumes the concepts which represent the process of meaning restoration.

#### The Key Category of Adjustment

What emerged from the data was that prior meaning structures, which did not account for the child's death (discontinuity), thus causing disorientation, were reinterpreted or adjusted in order to account for the child's death and restore a sense of meaning and purpose to the parents' lives. This strategy of reinterpretation was conceptualized as the category, Adjustment. The process of

adjustment was found to have the effect of changing aspects about the parents' personality as well as what they valued.

Variations in terms of the thoroughness of adjustment were also found among parents' reported experiences. In other words, the term Adjustment does not imply that meaning and purpose in life are necessarily restored to a pre-loss state. In fact, an adjusted meaning structure for some parents, may characterize a life which is viewed as being nothing more than a mere existence. On the other hand, an adjusted meaning structure may increase parents' appreciation of life and actually enrich their sense of life's meaning.

It was also discovered that adjusted views were not necessarily permanent. In fact, parents described themselves as moving "back and forth" between an adjusted view of the death, and disorientation. As Informant #7 explained, at times she believed that there may have been some reason for her son's death. Other times, she viewed the death as making no sense at all.

The adjustment of prior meanings was found to occur in one or both of two spheres: in the "here and now" and in the "grander scheme of things". "Here and now" was conceptualized as the view of life as the existence on earth, bound in time between the boundaries of conception and death. The "grander scheme of things" was conceptualized as the existence of life as unlimited to the boundaries of space (earth) and time (life-span).

The emergence of these concepts from the stories of the informants closely resembles the ideas of Koestenbaum (1976) who

described people as participating in two worlds, the particular and the universal. In the particular, people view and experience life as empirical, temporal, and fragile. In the universal world, life is viewed and experienced as transcendental, eternal, and indestructible.

### Adjustment of Prior Meaning Structures

#### The Property: Centrality of the Child's Life

Among parents for whom having a sense of meaning and purpose in life was dependent upon the existence of the deceased child's life, adjustments were made to derive meaning and purpose from other sources. This occurred in the realm of "here and now". These sources may or may not have existed prior to the child's death.

As would be expected, the lives of their other children became focal for most parents. This is not to suggest that the other child(ren) did not provide meaning for the parent before the deceased child's death. Rather, parents adjusted their prior assumption that all the children had to be alive for life to have meaning, to a view that although the one child was dead, meaning could still be found in the life or lives of the other child(ren).

In the case of one informant, although her deceased child was her only child, she found meaning in the hope of having another child in the future. In response to the investigator's prompt: "What would you say has kept you going?", Informant #4 stated,

I think honestly my desire to have another baby. When E. and I got married, I wanted one. I didn't want any more, I couldn't handle it. After M ... Anyone who has lost a baby has this desire, that

you have to have another one ... That's also made me think: Hey, I have to try and get my act together. I can't get pregnant and have another baby if I'm still so mixed up inside after losing M. That's made me do a little "getting my act together" quicker. If I didn't want another one, I don't think I'd ever be fine (11. 307-332).

As was suggested earlier, finding a sense of meaning in life may be more difficult for parents whose deceased child was an only child, when that child was the one in whom parents particularly invested their hopes and dreams in or the possibility of having another child was not available. This was found to be the case in the present sample. Informant #3 for example, described how the presence of her other son enabled her to adjust her meaning structure.

Without him I don't think I would have made it, because I had to think of him -- for his sake I couldn't just go off in a corner and cry for the rest of my life, because that wouldn't be fair to him. I didn't want him to not want to come home or stay here because it was too sad. For some reason I thought about it very early -- what it was doing to him. I couldn't let that happen. I didn't want to lose two (11. 237-334).

Some other variables which future research might address are the effects which the quality of the parents' relationship, the nature of the parents' relationship (e.g., a mother's relationship with an only daughter), or the duration of the relationship (e.g., the age of the child) to the deceased child have on parents' ability to make adjustments in terms of what provides meaning to their lives after that child's death.

Also in the realm of "here and now", some parents reported that meaning was found in their relationships with other people. As

Informant #2 explained,

Last year, when my mother was taken ill, they really needed me. I thought maybe that's the reason why I didn't do it [commit suicide], because I was going to be needed. I was able to go over and help them ... My dad really needed me. Afterwards I thought maybe that was a reason for my being here -- being needed (11. 361-370).

Informant #7 stated,

I try to keep going, mainly for my brother and sister because they were so good to me. Like when C. died, I really realized, I guess that was the first time in my life that I realized how close we were and how much they loved me. And, 'cause they gave me so much. I guess, I couldn't ... I wouldn't want to let them down ... (11. 767-772).

Some parents also described their new involvement in certain endeavors as providing them with a sense of meaning and purpose. Two of the informants for example, described their involvement in "The Compassionate Friends" support group as helpful. As Informant #3 explained,

I do know that getting involved with TCF helps. I truly believe in the group. Maybe that's where I put my efforts in ... I'm the one who has gone through this experience. I know how I was helped and therefore I put my effort and energy into that (11. 684-661).

As Informant #6 stated,

Every time you listen to somebody else you just ... it just really helps to help somebody else, to listen to them. I know how much it helped me to have somebody listen when I first went ... For the help

I got I can help somebody else, give it back (ll. 632-639).

Another aspect of adjustment which parents described, was the maintenance of meaning in the parents' memory of the child.

Numerous parents described their desire to keep the child's memory alive. Frequently, this was done by talking about the child. As Informant #2 explained,

It helps me when I talk of things we did together. Like the other weekend with A. [friend]. She said, "tell me some stories about E.". We talked about things he did as a little boy ... It's memories that you have ... It's when you think of him as a person, that's a comfort (ll. 278-287).

Some parents also engaged in certain rituals to acknowledge the child's past "physical" presence and their continued "spiritual" presence. As another informant described,

... we talk about L. a lot. We still celebrate her birthday. I started it when Q. was small. I'd always have a cake on her birthday. Now the kids kind of expect it. So we do it, because she's still part of the family (Inf. 5, ll. 193-197).

#### The Property: Nature of Life

Another aspect of adjustment in the realm of "here and now" was found in the descriptions of parents' views of the nature of life. As was discussed earlier, the event of their child's death destroyed parents' assumptions about life as being basically good in nature. Adjustment of this prior assumption was expressed in some parents' descriptions of having developed a greater awareness of the hardships and difficulties which are a part of life.



For some, this increased awareness extended to a greater appreciation of their own situation as compared to the perceived worse situations of others. When others' suffering was perceived as being as difficult or worse than their own, some parents described themselves as becoming more sympathetic and understanding of them. The following excerpts illustrate this aspect of adjustment.

I feel sorry for young people with all these tragedies. They have a young child die of cancer or they have children born unhealthy. I think you have to face that, and to never have those years that we had ... We had those years that were good. But God, when you have to face that in your twenties rather than when you're 39 ... (Inf. 1, ll. 794-804).

I look at my life, and I look at those Kurdish refugees or you look at three-quarters of the population of the world and I think, how could I think my life is unjust? I mean, they're struggling just to exist. It's so upsetting to watch those little babies that had died -- it was on the news one night. There were 15 little bundles of babies that had died. My heart went out to those parents ... I think I'm more empathetic. I'm more understanding than I was before (Inf. 5, ll. 418-460).

#### The Property: Finiteness of Life

A major theme which emerged from the stories of the informants, was the adjustment of parents' views on the finiteness of life in the realm of "here and now". As was described in the section, The Category of Discontinuity, previous non-death accounting meaning structures were characterized by parents' assumptions that the meaningfulness of "life" is limited to the context of its existence on earth.

It follows then that life is viewed in its "true" form as existing from the point of conception or birth and reaching its finiteness in death at an old age. In other words, life viewed as finite is acceptable when an old person dies. Death in youth is viewed as an unnatural interruption of the normal cycle of life.

In order to accept the finiteness of life in the case of their child's death, some parents focused on the meaningfulness of their child's life, despite the fact that the child "should" have lived longer. As Informant #5 explained,

... I know that L. was here as a gift to us, and she was here to show us something. And we learned a lot from her (11. 338-341).

Informant #8 stated,

... my feeling is that having T. for 16 years was a privilege I guess, if that's all we were allowed, that was it. But I feel that anybody who touches your life and then is lost, that there has to be something good come out of it. You have to have benefitted from having that person near you (11. 681-686).

Another adjustment which many parents made in the area of their assumptions about the finiteness of life, was to place the child's death in the context of the "grander scheme of things". This was characterized by a view of the child's life as infinite in terms of its continued existence in an after-life. Many parents described themselves as having developed an increased interest in the possibility of an after-life or as having become firmer in their beliefs that an after-life exists. An example of an adjusted view in this context would be that although the child's life is final in

the realm of the "here and now", he or she continues to exist in the "grander scheme of things".

This adjusted view was described as being helpful for most parents. Specifically, that view allowed parents the hope that they would one day be reunited with that child. As informant #6 stated,

... you just know that there's more than just here, and it makes you feel good. It doesn't take away the pain or the grieving or the fact that your child isn't here. You hang on until its your turn (11. 523-528).

As Informant #5 explained,

... I know I'll see L. again. I know there's an after-life, before I didn't. Again it's hard to explain how or why, I just know. And that's comforting (11. 187-189).

The belief that an after-life exists and that reunion with the child will occur was found to affect parents' views of their own death. The parents who held these beliefs reported that they were no longer afraid to die. In fact, one informant described herself as welcoming her eventual death:

I used to worry about not being alive to see my children grow up and to be here to help them. Now, if I were to go today, I'd be very happy. Because I feel like I want to see him (Inf. 3, 11. 229-232).

Those parents who expressed doubt about the existence of an after-life, described their intense yearning to have assurance of it. As Informant #2 described,

I'm not a religious person. I really wish I was. I wish I had religion. I envy people who truly, truly believe that there is a place that you go to after here (11. 239-241).

Informant #7 explained,

But now I certainly would like to believe there is something after. If I don't believe that then I'm not going to see C. again, you know? My brother ... he does believe that there is something after this. I wish, I wish that I did too. I wish I had as strong a conviction of that as he does, because that would make things easier. But I don't have proof ... I kind of hope that eventually I'll come to believe that there is something else (ll. 586-631).

This yearning for a belief in an after-life to give some meaning to the anguish which is experienced from the loss suggests that a simple measure of church attendance as an indicator of religiosity, as was used by Sanders (1980), is not sufficient to determine the effects of religiosity on bereavement. As Wuthnow, Christiano and Kuzlowski (1980) suggested, research which examines the relationship of religion to bereavement should address how people's conceptions of existence, including their beliefs in an after-life, incorporate death as a meaningful event.

#### The Property: Control Over Life Events

For many parents, their meaning structures prior to the event of their child's death were characterized by the assumption that they had power in determining the outcomes of life events. For many, the assumption was also held that a "greater being" was a source of power which operated to serve the same purposes as those which they themselves desired.

These parents described themselves as having arrived at an adjusted explanation for the death, in terms of the "here and now". Prior assumptions about the internal and external power to control

life events were reinterpreted in the form of the adjusted view that things happen which are beyond anyone's control. As Informant #3 explained,

I no longer believe it was God's will. I think it was an act of nature. He caught some sort of infection, and it caused his death -- not that God has willed that on him (11. 225-227).

As Informant #6 expressed,

I don't feel God called T. to be killed. I mean T. was killed because he had dark clothes on and he was on the wrong side of the road with his back to the traffic. It was his choice to do that ... you have to believe he chose to drink, chose to go ... It wasn't God's fault or my fault, or anybody else's. It took me a long time to accept that. I think I have now (11. 372-381).

Many parents adjusted their view of having power to control events of life to an acknowledgment that things happen which are beyond their control. However, some reported that despite that awareness, they continued to take measures, even increased measures, to prevent the occurrence of another loss. Informant #3 for example, described how she started to check up on her adult son before each time that she went to work. Informant #5 described how she started walking her other son to school every day, for fear that he might be hit by a car if he walked alone. This desire to maintain control illustrates the stubborn nature of meaning structures.

On the other hand, a more thorough adjustment is demonstrated in the comment of another informant who stated,

Now N. [another son] is in Mexico. If this had been T. I'd be a basket case -- like, what if something would happen to him? Now I figure it can happen at home ... If it's going to happen it can happen any time. I don't worry about things like that anymore (Inf. 6, ll. 351-357).

#### The Property: Existence of Order

What characterized many parents' prior assumptions of the existence of order were beliefs that the world operated in such a way that fairness and justice were maintained. An underlying assumption of that belief was that things happen for certain reasons: "good" reasons. For many, this prior view of order was adjusted because it did not account for the perceived unfairness and injustice of their child's death.

Of the parents who had experienced discontinuity and disorientation, a few stated that some "good" could be found in the death. This view placed the child's death in the sphere of the "here and now". Informant #3 for example, stated,

In a way I think it was better for him to go than to live being incapacitated. C. wouldn't have wanted that (ll. 123-125).

Informant #7 stated,

He was here only 17 years, but he had a good life, didn't have any great worries and he's not going to go through all the stuff that people go through in their lives that are really hard -- that make life really hard ... It's hard to find anything else that really makes sense (ll. 547-579).

Also in the sphere of the "here and now" were adjustments which two informants made to their prior assumptions about the role of other people in doing their part to ensure that order is maintained.

One informant recognized the fact that she had been wrong to assume that laws prevented people from driving drunk. Her response to that sharpened recognition was to become actively involved in educating people about the high incidence of alcohol-related accidents and in preventing future accidents. Essentially, the adjusted view of her prior assumption was that although order had not existed to the extent which she had assumed it to exist, education of people and the enforcement of stricter laws had the potential of correcting those flaws.

The other informant acknowledged that her assumption of the medical establishment as being trustworthy had been wrong. Her response to that adjusted view was to make the medical establishment aware that the adverse reactions to immunization which had caused her daughter's death could be prevented.

In the cases of these two informants, their prior assumptions of our society as an orderly institution were reassessed and adjusted. A new recognition that the world was not as orderly as they had once assumed resulted in an adjusted view that there were measures that could be taken to improve the conditions so that order could be restored.

Again, the message which emerges from these two informants' stories, is that prior meaning structures do not easily change. As Berger and Luckmann (1966) explained, when challenging definitions of reality present themselves, the existing internalized reality is intensified, reinforced, and reaffirmed in order to resist the threat of displacement which has been posed to it.

Although a lack of order, as it has been defined above, explained the deaths of their children, these women still expressed a basic faith in the potential of societal order to provide security to people. Meaning could be found "here and now" in the restoration of order, which would prevent situations similar to theirs from affecting the lives of others.

In the cases of those informants who concluded that their child's death could not be completely attributed to a fault of their own, of others, or of "God", an adjusted view of order became characterized by the view that "some things just happen for no reason". The following excerpts illustrate this adjusted view.

I suppose it's just something that you get. I suppose God doesn't really have anything to do with that ... I don't know. It's like trying to explain why you get the flu. I don't think anybody could tell us why he got what he did (Inf. 2, ll. 268-273).

I don't think there was any hand-guiding that went on that night. It was just -- it was chance that put her in the wrong place at the wrong time (Inf. 8, ll. 698-701).

I thought if I could understand the disease more, then I'd understand why. But that really had nothing to do with that part of it. It's just one of those things that happen (Inf. 10, ll. 123-126).

Another aspect of adjustment among some parents, in terms of assumptions about the existence of order, was a belief in the occurrence of their child's death as having some reason in the "grander scheme of things". In other words, although a reasonable explanation for the death could not be found, or was not believed to



exist in the realm of the "here and now," the belief existed that somewhere, sometime the child's death would make sense. As Informant #6 explained, it was helpful for her to believe that when she died, she would find out why her son had died at a young age. As Informant #5 stated,

... it's hard to explain how or why, I just know [there is an after-life]. And that's comforting too -- I really think that some day I will understand the things that I don't know. In that way, that's been a big change (ll. 187-192).

Informant #8 stated,

I think there has to be something above oneself to give some kind of reason to all this (ll. 624-631).

Informant #10 explained,

I believe there is a reason for why things happen -- good things, bad things, for whatever ... there's a reason. You might not know the answers or that reason, but there is a reason (ll. 446-449).

A view of the child's life as meaningful in the "grander scheme of things" can concomitantly give meaning to the life and death of the child in the realm of the "here and now". A belief in the fact that there is some "grand" reason for an untimely death, implies that there may also be some reason for why the child lived and died in the realm of the "here and now".

#### Effect of Adjustment on Values

For many parents, adjusted prior meaning structures were characterized by an increased awareness of the frequent and widespread incidence of hardship and difficulty in people's lives, a

realization of their own limited power to control events of life, and an increased recognition of the fragility of life. Viewing life from within this set of adjusted meanings typically had the effect of causing parents to re-evaluate the values which they had held prior to their child's death.

In essence, parents described an increase in their awareness of what is really important in life. The factors which were described as being the most important in life were similar in nature to the reasons which parents reported for not committing suicide. Other people were the reasons for not committing suicide and were also what continued to provide meaning in their lives thereafter. The following excerpts illustrate this effect of adjustment.

But I feel ... don't ignore your kids, because you may not have another chance. I will not miss anything with E. [other son]. I will cancel my arrangements to do it. Because I don't want to feel that I missed the chance (Inf. 3, ll. 398-403).

It's made me realize what's most important in my life ... The most important thing to me is my family ... I'd see my family when I felt like it, if it was good for me. Now it's more like, if they need me, I'm there in a second (Inf. 4, ll. 282-295).

I think your values change, your philosophies change. Suddenly you know what's really important. And you forget all the frivolous things that get in the way ... people are important. It's not material things that mean anything (Inf. 5, ll. 141-158).

I think that what has happened has made me realize that life is very short -- and the most important thing in my life is the family. I guess I do make an awful

lot more of the family now -- more than I did (Inf. 8, ll. 502-505).

Comparison to the Negative Case

As was explained in the beginning of the Findings section, the question of why one informant (#9) expressed immediate and complete acceptance of the loss of her son, whereas other informants found great difficulty in this, even over extended periods of time, guided the analytic procedure. Through the process of constant comparative analysis between all of the ten cases, it was discovered that the characteristics of Informant #9's meaning structure at the time of her child's death were similar in many ways to the adjusted meaning structures which were developed by the other informants to account for the death.

First, Informant #9 expressed that the loss of her one child did not cause her to lose her sense of life as being worth living. Rather, she stated that suicide did not even cross her mind because she wanted to live for her two other surviving children. This type of orientation was not shared by many of the other informants, who expressed an intense wish for their own death, despite the fact that they had other surviving child(ren).

Second, throughout the interview, frequent references were made to difficult experiences in her past. This suggests that she may not have had illusions about life as being characterized by only basically good experiences. Perhaps the prior knowledge she had of life as a difficult experience permitted the development of a meaning structure which accounted for the incidence of a child's death. Because of her ability to account for the experience, her

meaning structure was not threatened to the same degree as were those of the other informants who had assumed life to be basically good in nature. In a sense, although the child's death caused her great sorrow and pain, it did not present itself in the form of a meaningless crisis.

Third, a strong belief in an after-life gave her the assurance that her child continued to exist in a place where "God was watching over him". Although his life on earth had been short, it continued to have "eternal" meaning in its existence in heaven.

Fourth, a belief in herself as being powerless under the control of an all-powerful God who makes only the "best" decisions, allowed her to accept her child's death as something that "should" have happened. In her view, it was a situation over which she had no control.

Finally, a belief that order is maintained by a God who ensures order, permitted her to accept his reasons for "taking" her son as unquestionable. Therefore, she had no need to search for answers.

#### Factors Affecting Adjustment

Two factors which all of the informants described as being helpful were talking about their child and the experience of the loss and being understood. As Informant #5 stated,

That's how you get through things -- somebody listening patiently and allowing you to talk. This is always therapeutic. You can heal yourself really, if you're allowed to talk to someone who will listen (ll. 460-464).

As Berger and Luckmann (1966) explained, people who experience a disconfirmation of reality and find themselves having to re-orient themselves in a "new" reality, require contact with others who share those new meanings. This contact provides validation of that new system of beliefs, values, assumptions, and norms.

Perhaps this explains why parents reject the explanations or advice of others which do not correspond with their own views. Davidowitz and Myrick (1984), in their study of twenty-five persons who had experienced a death in the immediate family, also found that statements such as "it's God's will", "you have to get on with your life", or "be thankful you have another child" were perceived by parents as being non-helpful.

As Berger and Luckmann (1966) described, challenging definitions of reality, in this case the explanations which other people give to the child's death which do not "fit" in terms of the parents' meaning structures, are apprehended or resisted. This aids in the purpose of maintaining the existing reality construct. Although each of the informants had some connection with the support group and may therefore be atypical of the larger population of bereaved parents, talking about the experience with others who share a similar reality nevertheless appears to be an important facilitator of adjustment.

### Understanding Parental Bereavement: Implications

The grief resulting from the loss of a loved one is widely experienced. In fact, as cited earlier, it is recognized as an inescapable aspect of the human condition (Kessler, 1987). People lose their spouse, their parents, their siblings, and/or their relatives to death. These types of losses result in sadness and sorrow for many people.

What makes the experience of a parent's grief over a child's death unique from these other types of losses, is that for many parents, an entire collection of assumptions about life, society, the world, and/or the universe are called in to question. A child's death is typically viewed as being "wrong" or unnatural. Therefore, the experience leaves parents not only having to deal with the impact of that loss on their lives (e.g., missing the child's presence), but with a loss of faith in beliefs, values, assumptions, and norms they once had about the way the world should be: the way they "knew" it to be. Bereavement strikes parents at a deep level; a level upon which their whole existence is based.

As was described throughout the preceding discussion, a child's death has the potential of challenging parents to re-evaluate the meaning of life, to question the existence of a God, the limits and nature of His power, to ponder on the possibility of an after-life, and to question the order of the universe. These challenges were discovered as affecting changes in parents' relationships with others and also what they valued.

Recognition of the complexity of parental bereavement suggests that viewing the experience in terms of its occurrence in predictable stages is inadequate. The findings also suggest that defining recovery as a return to the pre-loss state is inapposite.

As was discussed in the Review of Literature section, many scholars have attempted to explain the experience of grief as a progression through various stages. What is implied by this view of grief is that a normal grieving experience is expected to reach a final stage of resolution. Raphael (1988), for example, described the relinquishment of bonds with the deceased person and reintegration with the world as signals of the completion of the grieving process. The findings of the present study suggest that the lasting difficulty which some parents experience specifically in the area of finding meaning in their child's death has not been accounted for by existing stage theories of grief.

According to the examples from the stories of many of the parents in this sample, people who once assumed that the world was basically fair and just, that somehow things "equal out", or that people's fortunes are determined by their deeds are changed when a child's death is experienced. These changes occur on such a deep level that it appears doubtful that people will ever be the same person they once were before their child's death.

Understanding the complexity of parental bereavement has implications on a community level as well as for professionals who deal with parents. Allowing and encouraging them to talk and understanding the deep level at which the experience affects them

appear to be the most effective methods of offering support. Providing explanations or advice that do not correspond with their views of the experience seem to serve only the purpose of causing them to become angry and frustrated.

The findings of this study emphasize the important role which a group such as The Compassionate Friends has in providing support. This is done through the provision of an environment where participants are free to share their experience with other people who listen, who understand their experience, and do not attempt to provide explanations or advice.

Finally, this increased understanding of parental bereavement also brings forth an element of hope. Although the experience caused the collapse of prior meaning structures for many parents, the potential of restoration of meaning through an adjusted orientation to life was also described as being possible.



### Strengths of the Study

The purpose of this study was to attempt to understand how parents explain, understand, and find meaning in the experience of child loss. The specific goal was to develop a theory from the data collected, which accounted for the stories of each of the ten informants and therefore explained the variation among them.

Two major strengths of this study are the quality of the data collected and the method by which those data were analyzed. First, by allowing parents to "tell their story" in their own words in the form of an informal interview, the investigator was permitted to "see" the worlds of the informants as they did. This enabled the investigator to gain knowledge about the "real" experience of the phenomenon of parental bereavement.

Second, using the method of grounded theory, comparing concept to concept and case to case, enabled the investigator to become sensitive to differences and similarities between the various stories and to what accounted for the variation among them. This process allowed for a theory to develop which remained faithful to each informant's account of their experience.

Substantive codes were developed from the data themselves. Pre-existing codes and/or categories were not applied to the data. This permitted the investigator to develop an account of the phenomenon which fit the data. By using this method, the danger of forcing the data to fit pre-existent concepts and hypotheses was avoided. Thus, the danger of merely collecting evidence to prove pre-existent notions of relationships between variables was also

avoided. As Glaser and Strauss (1967) purported, an account which corresponds closely with the data is the underlying basis of a grounded theory.

The parameters of this study were delineated by the fact that the present sample was obtained from a support group and consisted of only women who had experienced the unexpected loss of a child. However, the fact that the data obtained from these informants are abstracted as characteristics of larger concepts, may make the concepts generalizable to other people who are also experiencing the phenomena, such as non-support group members, fathers, and those parents who have lost a child who has suffered a period of terminal illness.

Data obtained from further study of the phenomenon among various other informants would increase the richness of the concepts discovered in this study by adding properties and their dimensions, without necessarily changing the meaning of the basic concepts. For example, in the present study, a category related to the experience of child loss was the nature of parents' meaning structure at the time of their child's death. This category affected how the parent accounted for the loss.

One example of the data from which this category was generated, was one mother's report of how, prior to her child's death, she had believed that she could control the outcomes of life's events. After the child's death, she experienced a sense of distrust in the new recognition of her inability to control things. Although the belief that life events are controllable may not be true of all

people, or may differ in terms of its steadfastness, the relationship of the concept, Prior Meaning Structures to how the death is accounted for remains. As Glaser and Strauss (1967) stated: "In short, the discovered theoretical category lives on until proven theoretically defunct for any class of data, while the life of the accurate evidence that indicated the category may be short" (p. 24).

The present study has engendered a greater understanding of the phenomenon of child loss by discerning the issues and problems which are experienced by parents. Increased sensitivity to the issues and problems which emerged from the stories of the mothers in this sample may be generalized to the wider population of bereaved parents. However, as discussed in the following section, caution with regard to generalization of the results should be taken.

### Limitations of the Study and Suggestions for Future Research

Many questions about the phenomenon of understanding, explaining, and finding meaning in the experience of child loss have remained unanswered. This section outlines the major limitations of this study and identifies areas from which future research could benefit.

1. The present study included only mothers. Therefore, possible differences and/or similarities in the experiences of fathers were not identified. Males in our society have typically been socialized to assume the role of bread-winner (Mackie, 1987). For many males, the responsibility to provide practical support for the family accompanies this role. It is possible that among males who view their role in the family as bread-winner first, and parent second, a child's death may be interpreted differently than it is by mothers, who are typically socialized to be the primary providers of emotional and nurturant support to their children.

2. The present study did not control for the possible effect which a parent's involvement in a career could have on their experience of child-loss. As was discovered in this study, the central role which a child held in providing a sense of meaning and purpose to the parent's life was related to a resulting collapse of the pre-existent meaning structure. It is possible that parents who derive a strong sense of meaning and purpose in life from their occupation or career may be less susceptible to a collapse in their meaning structures. In a sense, a meaningful career could buffer the effect of the meaning which is lost from a child's death.

3. As was briefly addressed in the Findings section, some evidence emerged that parents whose deceased child was an only child perceived their situation as worse than that of parents who had other surviving children. More rigorous analysis of the relationship between the number of children and the degree of disorientation is required.

4. Another limitation of the present study is that the variable of length of time since the child's death to the time of the interview was not controlled. Future studies may investigate the effect of the passage of time on parents' ability to explain and understand the loss. For example, is a greater amount of time since the death related to a greater degree of adjustment? Does adjustment remain constant over time?

5. The theory which emerged from the present study consisted of three distinct related phases: discontinuity, disorientation, and adjustment. It should not be assumed however, that these phases of bereavement necessarily occur in an orderly progression. Rather, the data have indicated that parents may move back and forth between the phases. What remains to be learned is what types of factors allow for movement toward an adjusted set of meanings which explains and accounts for the death, and what types of factors inhibit the reinterpretation of non-death accommodating meaning structures.

6. As was also previously addressed, the relationship of religion and parental bereavement also requires further investigation. Future studies should focus on parents' religious beliefs in terms of their conceptions of God and the existence of an

after-life, rather than using quantitative means to measure religiosity.

7. The present study has represented the beliefs, values, assumptions, and norms which may be more typical of middle-class parents. Future research should examine possible differences in meaning structures of parents in other socio-economic groups. For example, parents from a lower socio-economic group may typically have different expectations of life. This may be especially true when past experiences have resulted in a view of the self as being a victim of surrounding circumstances, not as a determiner of consequences. It would be reasonable to question whether or not people who have fewer illusions about life experiences as working in their favor are less susceptible to disorientation resulting from a child's death.

8. Another factor to consider is that the parents in the present sample did not expect their child's death. Among parents who anticipate the eventual death of their child after an extended period of illness, meaning in the forthcoming death may already have been found before the actual death. Past research has indicated that there are no differences in reported bereavement intensity between parents who survive the sudden death of a child, and those who survived an anticipated death (Klass, 1988; Miles, 1985). However, it is possible that the process of finding meaning in the death may differ among parents in these differing situations.

9. The present study included only the stories of parents who had had some connection with a local support group. It is possible

that this characteristic designates those parents as being atypical of the larger population of bereaved parents. Future research might investigate whether or not parents who do not express a need to attend a support group have the same experiences of discontinuity and disorientation as was identified among the parents in the present sample.

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APPENDIX A

LETTER: PURPOSE OF STUDY AND REQUEST FOR VOLUNTEERS



THE UNIVERSITY OF MANITOBA

FACULTY OF HUMAN ECOLOGY  
Department of Family StudiesWinnipeg, Manitoba  
Canada R3T 2N2Ph. (204) 474-9225  
FAX: (204) 275-5299

Dear members of The Compassionate Friends (Winnipeg Chapter):

My name is Millie Braun, and I am a graduate student in the department of Family Studies at the University of Manitoba. I became familiar with your group approximately one year ago when I met with your leaders Ken and Pat Pinch, who provided me with resources for a paper I was writing on the subject of child loss. I have remained interested in the experience of parents who have suffered the loss of a child. Therefore, I have chosen that topic for my thesis, which is a requirement for my Master's degree.

Specifically, the focus of my interest is to explore the process of understanding, explaining, and finding meaning in the experience of losing a child. My request of your group is to privately interview ten members who are willing to share aspects of their bereavement experience with me.

The interview questions are open-ended, and there are no right or wrong answers. The interviews would take place at a location of the interviewee's choice. The length would vary depending on the amount of information volunteered by the informant. A second interview may be requested for the purpose of clarification of information. The interview(s) would be tape recorded, and transcribed word for word. After it (they) has (have) been transcribed, the tape would be destroyed. The written transcript would be returned to the interviewee for editing. Desired changes would be made before the transcript is used for data analysis. The completion of a brief demographic questionnaire will also be requested.

Please note that the interviewee is free to withdraw from participation, or withdraw information at any time during or after the interview.

All records will remain confidential. The transcript will be coded with a number to enable only myself to identify the informant. Names used in the interview(s) will be deleted or a pseudonym will be used. The list of identifiers will be destroyed after the transcripts have been edited.

If you are interested in participating in this study, please inform me or Pat Pinch. I will then select ten volunteers and contact you by telephone to arrange a convenient time and place to conduct the interview.

Your willingness to participate is greatly appreciated.

A copy of my completed thesis, including my findings from the interviews, will be submitted to your chapter.

Sincerely,

Millie Braun

Please contact me at 663-0226.

**APPENDIX B**  
**INFORMED CONSENT**

INFORMED CONSENT FORM

I have read the enclosed letter, and agree to participate in a tape-recorded interview under the conditions that the tape recording of the interview will be destroyed immediately after the interview has been transcribed, my identity will remain confidential, names mentioned in the interview will be deleted or substituted with pseudonyms, and I will have the opportunity to edit the written transcript of my interview to meet my approval before the data is analyzed. I also understand that I may withdraw from participation, or withdraw information at any time during or after the interview.

I am also willing to be contacted for a possible second interview to which the above conditions also apply.

NAME.....

PHONE NUMBER.....

SIGNATURE.....

DATE.....

APPENDIX C  
TRANSCRIPT APPROVAL

Dear

June 19, 1991

I have enclosed a written transcript of our interview on \_\_\_\_\_. As I informed you, I require your approval for this transcript to be used for data analysis.

Please be reminded that your identity will remain confidential. Also, all names have been substituted with arbitrary initials.

If this transcript meets your approval for data analysis, please sign below:

SIGNATURE \_\_\_\_\_ DATE \_\_\_\_\_

Or, if changes must be made to meet your approval, please indicate on the reverse side of this letter, what revisions you wish to make, and on which pages of the transcript they should occur.

If this transcript meets your approval, provided the requested revisions are made, please sign below:

SIGNATURE \_\_\_\_\_ DATE \_\_\_\_\_

\*\*\*\*\*

Also, to ensure that I have all the necessary demographic information, may I request that you answer the following questions?

1. What was the date of your child's death?
2. What was the cause of your child's death?
3. How old was your child when he or she died?
4. How soon after the death did you join Compassionate Friends?
5. Are you still a participating member?
6. If not, when did you stop participating?
7. What is your age?

\*\*\*\*\*

Please return this letter only, as soon as possible, in the stamped envelope which I have enclosed. The enclosed copy of your transcript is for you to keep.

Thank you again for your participation in this study.

Sincerely,

Millie Braun



APPENDIX D

LETTER TO RESEARCH ETHICS COMMITTEE

SUBMISSION TO ETHICS COMMITTEE  
FACULTY OF HUMAN ECOLOGY

TITLE.

An Exploratory Study of the Reconstruction of Shattered Meaning Structures in the Experience of Parental Bereavement.

INVESTIGATOR.

Braun, M. J.

GRADUATE ADVISOR.

Berg, D.

DEPARTMENT.

Family Studies

PURPOSE.

The goal of this research is to examine the experiences of bereaved parents in regards to their struggle to understand, explain, and find meaning in the loss of their child. Previous research in the area of parental bereavement has focused on emotional and psychological consequences of grief. However, little attention has been directed toward examination of the process through which the experience comes to be "understood" by parents. It has been suggested that this aspect of bereavement may be a key factor in determining outcome of grief (Miles & Crandall, 1983).

SUBJECTS.

The subjects for this research project will be ten bereaved parents who are members of a local chapter of The Compassionate Friends, a support group for bereaved parents. The leaders of the chapter have expressed an interest in this project and have offered to assist in the process of identifying individual members who are willing to be interviewed. A letter which explains the purpose of the project, and requests for volunteers will be forwarded to the group through the leaders of the chapter.

BENEFITS AND RISKS.

Volunteer informants may benefit from participating in this study because it provides the opportunity to talk about the child or express thoughts and feelings regarding the death. Because informants will be volunteering to offer information, it is assumed that they are willing to share their experience.

Informants will also receive a synopsis of the findings when the research is completed.

The research will not pose any risks to the informants as those interviewed will have been self-selected and will have expressed a willingness to discuss the experience of their loss. All records will remain confidential, and will be coded for identification by the researcher only. Names used in the interview will be deleted, or replaced with a pseudonym.

PROCEDURES.

A letter which explains the purpose of the study, outlines the procedure of the interview, assures confidentiality, and requests for volunteers will be given to members of The Compassionate Friends at one of their regular meetings. Interested members will identify themselves to the chapter leaders. The chapter leaders will then refer me to those individuals. If less than ten individuals volunteer, I will attend one of the meetings and make a personal request for more volunteers.

After contacting the interested volunteers by telephone, a convenient time and location for an interview will be arranged. The format of the interview will be open ended. Some general questions have been prepared for use as a guide during the interview. Informants will be assured that there are no right or wrong answers.

The interview will be tape recorded. The tape will be transcribed word for word; names will be deleted or substituted with a pseudonym. The tape will then be destroyed. The transcript will be returned to the interviewee(s) for editing in order to meet his or her approval. A number will be used to code the written transcript, which corresponds with the interviewees' name. A record

of the codes which identify interviewees will be stored in a separate location. These records will be accessed only by the researcher. They will be destroyed upon completion of the research project.

INFORMED CONSENT.

Participation in this study is voluntary. Interested informants will be asked to sign a consent form signifying that they have volunteered to participate under certain specific conditions.

REMUNERATION.

Participants will receive no payment for their participation in this study. A brief synopsis of the research findings will be presented to each informant.

INFORMATION FROM NON-PERSONAL SOURCES.

Not applicable.

CONFIDENTIALITY.

This has been discussed above under the Procedures section. Confidentiality is assured to potential volunteer informants as outlined in the attached letter.

REFERENCE

Miles, M. S., & Crandall, E. K. B. (1983). The search for meaning and its potential for affecting growth in bereaved parents. Health Values: Achieving High Level Wellness, 7 (1), 19-23.

APPENDIX E

RESEARCH ETHICS COMMITTEE APPROVAL

## FACULTY OF HUMAN ECOLOGY

## UNIVERSITY OF MANITOBA

## APPROVAL FOR RESEARCH PROPOSAL INVOLVING HUMAN SUBJECTS

This is to certify that:

Dr. Dale Berg and Ms M.J. Braun

in the Department of Family Studies

presenting a proposal for a research project entitled:

An Exploratory Study of the Reconstruction of Shattered  
Meaning Structures in the Experience of Parental Bereavement

The Faculty Ethics Subcommittee is satisfied that the appropriate  
ethical criteria for research involving human subjects have been  
met.

Members of the Subcommittee:

<u>Name</u>	<u>Position</u>	<u>Department</u>
G. Sevenhuysen	Associate Professor	Foods and Nutrition
N. Fetterman	Associate Professor	Clothing and Textiles

Date: April 2, 1991

Dennis W. Fitzpatrick  
\_\_\_\_\_  
Subcommittee Chair

APPENDIX F  
INITIAL CODES

After-life belief	A <b>belief</b> in an <b>after-life</b> or life "beyond", and/or reincarnation, and/or ability to connect with the deceased in the life "beyond"
After-life belief wish	A wish for a <b>belief</b> in an <b>after-life</b> or life "beyond", and/or reincarnation, and/or ability to connect with the deceased in the life "beyond".
After-life doubt	A <b>doubt</b> in an <b>after-life</b> or life "beyond", and/or reincarnation, and/or ability to connect with the deceased in the life "beyond".
After-life evidence	Statements which describe <b>evidence</b> of an <b>after-life</b> , life beyond, reincarnation, etc.
Anger	Expressions of anger regarding the death or events around the death or grieving. e.g., towards God, self, others, etc.
Change in enjoyment	Reference to a <b>change</b> in the way life is <b>enjoyed</b> . e.g., "I don't enjoy life anymore." "I don't know if I'll ever have that ecstatic feeling again."
Changed life	Factors or aspects of life that have <b>changed</b> . e.g., time spent with family changed family relationships (e.g., "I don't talk to my mother anymore")
Changed life: No	Factors or aspects of life that <b>haven't changed</b> -- constant factors. e.g., working, taking care of children
Changed life-view	Reference to a <b>changed life-view</b> . e.g., life is <b>fragile</b> a feeling of <b>distrust</b> about life. life is not something to be <b>taken for granted</b> .
Changed person	Reference to having <b>changed</b> in some way that makes the person different than they used to be; a <b>personality</b> change. e.g., "You're not the same person anymore." "I used to be a city-type person. Now I wouldn't care if I stayed alone in the middle of the prairies."



Changed values	A <b>change</b> in values regarding what is important or not important, or a shift in the degree of importance of values.
Cheated	Because of the death, the person feels <b>cheated</b> by life. e.g., "I feel cheated. I'll never see his children."
Control: lack of internal	Recognizing <b>own lack of control</b> over life events. e.g., "Do they just assume their kids will grow up, like I did?" "And so after you've done all the things you think are right, and then your son dies ... It's like a total lack of control."
Control lack: accept y/n	<b>Acceptance or non-acceptance</b> of own lack of control over life/death events.
Control: in random world	Reference to their past or present illusion of <b>having control</b> in a <b>random world</b> . e.g., "You know these horrible things happen. You just don't think they're going to happen to you."
Control: external	Reference to a belief that <b>control</b> and/or order <b>exists</b> in life and in the world. Life and the "world" makes sense. e.g., "I do believe He controls everything."
Control: lack of external	Reference to a <b>disbelief</b> that control and/or order exists in life and in the world.
Control desire	<b>Desire or attempt to control</b> life/death events. e.g., "After he died I thought, Is he okay, does he need me?" Being more careful with other children.
Death-own	References to own death. e.g., Wishing to die, reference to death as a way of reuniting with the child, a lack of fear of death.

Death: good	Finding something good or reassuring regarding the death. Something good has evolved from the death. e.g., "We learned a lot from her." "He would have suffered all his life." "He won't have to go through hard things in life. He's in a better place."
Death: Reactions	<b>Reactions</b> to the <b>death</b> or to the news of the death (particularly soon after the death). e.g., feeling numb, being in a daze, feeling overwrought, hysterical, disbelief.
Deconstruction	Reference to the <b>event</b> of their world shattering.
Deserve: no	Reference to certain people <b>not deserving</b> to die -- who <b>should</b> or <b>should not</b> die. Certain deaths are not justified, in a more general sense. Different than "unfair", where specific conditions around that particular death are viewed as being unfair. e.g., healthy people young people
Deserve no: accept/non-accept	Statements which suggest that the person <b>accepts</b> or <b>does not accept</b> the fact that certain people do not deserve to die.
Doing to	The idea that someone or something <b>did this</b> to them. Referring to oneself almost as a victim. e.g., "I didn't want to do to them what has been done to me." "Why did you do this to me?"
Expected: no	Death was <b>not expected</b> . Person was surprised by the death. e.g., "He had been so well..." "As far as we knew he was fine -- he would lead a normal life."
Friends	Reference to <b>keeping</b> or <b>losing</b> friends after the child's death.
Future	Reference to the death affecting person's view of the future.

God-Belief	Statements affirming a belief or a disbelief in God.
God-Belief: changed	Belief or disbelief in God/religion prior to the death has changed.
God: Resp./Not Resp,	God is or is not responsible for the death.
Grief Cope	Self-directed, purposeful attempts to manage or cope with the experience of grief. e.g., "I would read and read. I would try to escape in that way."
Grief Description	Descriptions of the experience of grieving, including symptoms or effects of grieving. e.g., not sleeping, nightmares, physical pain, depression, panic attacks, suicidal thoughts, missing child, withdrawing, not wanting to be alone, loneliness, keep worrying about child, fear of forgetting, searching for deceased.
Grief Process: Right or wrong	What one is supposed to do, what is alright in grieving or what one is not supposed to do, what is wrong to do in grieving (e.g., "don't go back to work until you're ready").
Grief validation	People validating or affirming their own grief or referring to others who validate their grief. e.g., "I feel the way I feel, and I will feel the way I feel. If you don't like it that's your problem."
Guilt: Grieving	Feeling guilty about the manner in which one is grieving. e.g., how it affects others, doing it right, meaning it.
Guilt: Prevention	Expressions of feeling guilt about not preventing the death. What could have or should have been done.
Guilt: Prior	Feeling guilty about things that could have or should have been while the child was alive, prior to the death.

Help: yes or no	<p>Statements about what <b>helped</b>.  e.g., "The nurses were good. They talk to you, and they got me sleeping."  -<b>feeling understood</b> by someone, or reading material  -being able to talk about the experience  -<b>receiving support</b> from others.  Statements about what <b>did not help</b>.  e.g., taking anti-depressants  getting away</p>
Holding up deal	<p>Reference to feeling that they were holding up their end of the deal in life.  e.g., Taking up responsibility as parents  Did everything they could do as parents  Have always done the "right thing".</p>
Immune	<p>References to prior beliefs and/or assumptions about being immune to tragedy.</p>
Know	<p>Having intuition / feelings / <b>knowledge</b> regarding the death without having actual information.  e.g., "I knew he was gone"  "... you know how you know these things?"  "I always had the feeling that something was going to happen."  "I knew something was wrong."</p>
Marriage strain	<p>Statements referring to <b>problems</b> or <b>stressors</b> in the <b>marriage</b> relationship which are results of the death and/or grieving.</p>
Others' behavior	<p><b>Behaviors</b> or actions of <b>others</b> (e.g., friends, professionals) in response to the death.  e.g., "The doctor was so matter of fact."  "The doctor and nurse just stood there behind the desk and stared at us."</p>
Others' grief	<p>References to aspects of other people's (e.g., family members) grief, or their reactions to the death; how others' grief affects the bereaved (e.g., "I couldn't stand to see his face").</p>

Others say	The things <b>other people</b> say to the bereaved regarding the death. e.g., peoples' comments, advice: "You'll get over it."
Out of Touch	Expressions of feeling <b>out of touch</b> , disconnected from or different than others, disconnected from the world, what's going on in the world, and/or feeling misunderstood. e.g., "...suddenly it wasn't the same because all these people had all of their family." "I wasn't in the same category, and so the things one would laugh about and discuss didn't mean anything to me."
Partner: Different	<b>Partner</b> is perceived as grieving <b>differently</b> . e.g., references to husband not talking about the death.
Preventability	References to the death as being <b>preventable</b> or <b>unpreventable</b> .
Purpose in doing: No	Describing feelings of <b>not</b> having a <b>purpose</b> in <b>doing</b> things. e.g., housework, cooking, working.
Purpose in living: No	Describing feelings of having <b>nothing</b> that is perceived as worthwhile to <b>live for</b> . Feeling that they have no <b>purpose</b> in living. e.g., "all my strength went with him. There doesn't seem to be much for me to fight for anymore."
Purpose in living: Yes	<b>Reasons</b> given for <b>going on</b> living, not just limited to what prevents people from committing suicide. e.g., wanting a good life for other children wanting more children
Purpose need: for death	Expressing a <b>need</b> or desire for the death to have some <b>purpose</b> . e.g., "If they would have isolated the virus, perhaps they could have prevented someone else's death."
Reason for death: No	Feeling that there is no good reason for the death. e.g., "I don't think I needed to lose my child to become a better person." Being upset when told: "God didn't want your father to go alone."

Religiosity	References to religious beliefs or views. Religiosity increased or decreased since the time of death?
Religiosity: questions	Reference to <b>questioning religion</b> since the time of the death. e.g., the death calls to question religious beliefs that were once held or not held, or the death arouses questions regarding religiosity.
Religiosity: wish	Reference made to <b>wishing</b> for own <b>religiosity</b> .
Response: action	What person did in <b>response</b> to the event of the death. What kind of <b>action</b> they took. e.g., start a prevention program increase awareness in medical community participate in a support group.
Self towards others	A change in <b>self</b> relating to <b>others</b> , or reactions of self toward others. e.g., less tolerant more sympathetic
Shouldn't be	Somehow things are not as they <b>should be</b> regarding the death.
Suicide: why not?	Why people <b>do not commit suicide</b> . What keeps them from doing it? Different from what provides meaning, purpose, or satisfaction in living. e.g., "...this is no good. I'm doing to my parents what has been done to me." e.g., "The nurse was walking with me. It seemed strange. It was usually me walking with people." e.g., "We can't take a family portrait when someone is missing." e.g., "You always see this boy -- yours is dead and hers is alive."
Unaccept	Conditions that make the death unacceptable. e.g., "He died after surviving a disease."
Unfair	Referring to the specific factor about the death as being unfair. e.g., wrong cause, wrong time

Unpleasant reminders	Reference to reminders of the death or events around the death that are unpleasant or upsetting. e.g., Driving by the child's school.
Why	Asking <b>why</b> the child died. Why it happened to them. e.g., "You're constantly asking why?"
Why: Need details	Asking " <b>why?</b> " A desire to know the <b>details</b> surrounding the death. e.g., "Where did he fall, how was he lying?"
Why: Explanation	Reference to a past or present <b>explanation</b> or possible explanation for <b>why</b> the child died. May also indicate parent's explanation of the purpose behind the death. e.g., <b>God</b> : "It was God's decision" <b>Self</b> : "I drank that beer, that's why my baby died." <b>Others</b> : "It was the doctor's fault." <b>External</b> : some unknown or unidentified external power caused the death to happen.
Why: No explanation	<b>No explanation</b> for why the child died. e.g., "It's like trying to explain why you get the flu. I don't think anybody could tell us why he got what he did."
Why search	Statements referring to the person's <b>search</b> for answers to questions such as "why him?" "why me?", "why?". A search for an explanation.
Why search: No	Accepting situation that answers are unknown. <b>Not searching</b> for answers. May include belief that answers will be discovered some day, perhaps in another life.
Worse	Conditions or situations regarding the death, that make it <b>worse</b> than others' grief, or what could be worse about the person's own situation. e.g., fact that death was sudden, child was an only child, child committed suicide, other losses also experienced.

APPENDIX G

EXAMPLE OF HYPOTHESIZING MEMO



## HYPOTHESIZING MEMO

JULY 28, 1991

It seems as though people's views on the "order of life" prior to the death of their child affects the amount or level of deconstruction of their world after the child's death (crisis).

There are two extremes: on the one hand, is the person who believes they are invincible: all their life they've been in charge and have basically gotten what they expected (e.g., "after spending 6 years in Africa, I thought I could handle anything", "all my life I've taken control, 'you've got a problem -- do something about it'").

On the other hand, is the person whose view of life may not be so clear-cut, or so orderly (e.g., the abused woman, daughter of Alcoholic parents).

I believe that the person who believes they have a greater degree of control in shaping their destiny and determining the outcome of events, will experience a greater degree of deconstruction than will the person who did not have those beliefs. That person may already have developed a "reality" that accommodated for "crisis" situations. The degree of deconstruction will vary, depending on the type of world view the parent held.