

Meaning-making in bereaved parents: Process and outcome

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Abstract

Meaning-making in Bereaved Parents: Process and Outcome

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The primary purpose of this research was to examine the process of meaning-making in bereaved parents. Through a narrative inquiry I investigated how parents described their process of growth and making meaning. Sixteen parents whose children died from an illness provided descriptions of their bereavement and meaning-making process. Thirteen of those parents participated in a face-to-face interview (11 parents) or responded to the same interview questions in written form (2 parents). The remaining three parents provided written answers to an abbreviated version of the interview only. Meaning-making was defined as a parent's experience of having grown, found benefit or a purpose in life as a result of their child's death. The qualitative interview and written answers to questions explored the parents' bereavement experience and whether they experienced growth, benefit or purpose. The qualitative findings show a clear pattern of meaning-making over time. In the early phase after the death, parents who eventually found some meaning in the death of their child experienced great anguish, sadness, betrayal, and shattered assumptions. Parents tried to make sense of the illness but did not seem to try to make sense after the death. In the early period after the death, parents instead questioned their beliefs. Parents went through a period of trying to find meaning (Attig, 2001) where they were receptive to the environment and any cues that facilitated their existential

questioning. After a period of time, the meaning-making parents reported that they needed to change; they reached a cross-roads and had to make a decision how they were going to continue living their lives. Once some of their spiritual beliefs had been reconciled and parents felt validated in their experience through significant others such as a support group, parents made a decision to re-work their priorities, values, commitments, actions, and relationships. The parents who found meaning were committed to creating a legacy for their child through their actions. This helped sustain the relationship with the child and maintained the role of parent. This process of meaning-making was then discussed in relation to the Dual Process Model (Stroebe & Schut, 1999). Some support for the model and differences between the data and the Dual Process Model were noted.

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I would like to dedicate this work to the young children on whose legacy I hope this work has contributed.

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MEANING-MAKING IN BEREAVED PARENTS: PROCESS AND OUTCOME

Overview

Birth and death are the only common events among living beings. Yet for Western culture, the inevitability of death generally leaves us feeling anxious and wanting to avoid or deny it. When we lose a loved one, we are usually faced with questions of mortality, what life is about, and the purpose of life. Because death is generally ignored or denied in Western culture, those who are grieving for a death may also often be denied sufficient opportunities to explore their experience and possibly find meanings from the death. Bereaved persons often perceive a lack of support from friends and family as time goes on which potentially challenges an individual's efforts for finding meaning. This death anxiety and waning support are two of the many variables that make the pursuit of meaning after loss difficult. Yet research demonstrates that people both initiate the search for meaning and find meaning from death.

The "scientific" study of bereavement has been documented since the early 17th century (Parkes, 2001, 2002). Since that time, physicians and researchers, such as Darwin, chronicled both the process and outcome of loss. However, it was Freud's (1917) *Mourning and Melancholia*, which propelled the study of grief and loss into the mainstream arena of psychology. Freud's theory of "grief work" laid the foundation and set the assumptions for our understanding of grief for almost a century. However, in the last 20 years, the assumptions about the process, purpose and outcome of grief have been challenged. Researchers have proposed new theories that incorporate other fields of research such as attachment theory and emotion

theory, while other researchers argue for bereavement specific models (M. Stroebe, Hansson, Stroebe, & Schut, 2001).

The literature on bereavement, both theoretical and empirical, has largely focused on spousal loss late in life. Because this loss can be considered a normative event, one may question whether the bereavement theories and research outcomes can be generalized to the non-normative loss of a child. Additionally, much of the literature chronicling the sequelae of loss focuses on the negative outcomes such as depression, psychiatric symptoms, and heightened mortality. In the last decade, researchers and theoreticians have begun to look at some of the positive outcomes of loss. This shift in focus allows researchers to investigate more thoroughly the complexity of the bereavement experience. However, the process by which people engage in making meaning has not been well documented.

The initial interest in this work stemmed from my years working as an art therapist in paediatric oncology. Over the years, I noticed that parents coped with the illness, and in some cases, death of their child in a variety of ways. Because we did not follow the parents after their child died, I often wondered “how they were doing”. I wondered if the coping skills they used while their child was ill helped them after their child died. And particularly, I wondered if any of the parents experienced growth or a positive change in themselves. The purpose of this dissertation research then, is to describe the process or course of bereavement as described by bereaved parents with a focus on how parents come to find meaning from the loss of their child. While the focus will be on the process of finding meaning, the outcome, or the content of the meaning, will also be described. The subject areas that will inform this

dissertation research are: a) bereavement theory; b) empirical research in bereavement with a focus on child loss; and c) theoretical and empirical research in meaning-making.

Theories of Bereavement

Freud's Grief Work Hypothesis

The legacy of Freud's work on grief has been both a benefit and a detriment to the field of thanatology, the study of death. The benefit has been that his description of grief provided a foundation from which others could begin bringing the discussion into mainstream research. Freud stated that grieving is an act whereby the libido is withdrawn from the love object and all attachments to this object. With time, the ego becomes free and can invest in other attachments and the person returns to *normal*. The bereaved person follows a predictable course of initially experiencing *acute grief* in which the griever comes to understand, accept, and begin to cope with the loss. This phase lasts 3-12 weeks, and is followed by the *mourning period* where attachment is gradually withdrawn from the one who died which can last 1-2 years. At the conclusion of this period, the person is said to have worked through the loss as manifested in the person's return to his/her "*normal*" emotional life. The grieving process was primarily an intra-psychic one and some expression of grief was essential. This process was considered the standard normal course of bereavement. Therefore, the critical features of Freud's model were: a) grief is intra-psychic; b) one must confront the loss; c) the purpose of grief is to relinquish all attachment to the deceased; and, d) one returns to normal. An absence of emotional expression was a

sign of pathology. It was not until the end of his life that Freud conceded that some losses are irreconcilable (Sanders, 1999).

The latter part of the 20th century has seen a challenge to Freud's theory (Hagman, 2001; M. Stroebe, 1992, 2001; M. Stroebe & W. Stroebe, 1991; Wortman & Silver, 1989, 2001). Prime refutations include: a) bereavement cannot be described in a stage model; b) grief is not just intra-psychic but also interpersonal; c) grieving includes a variety of emotions, not just sadness; d) the return to "normal" functioning does not mean a return to previous functioning; and, e) denial is an important component of grieving. Additionally, the 'normal' course of bereavement has been derived from clinical samples (Freud, 1917; Lindemann, 1965) and elderly samples (Parkes, 1975; Parkes & Weiss, 1983), thus, potentially skewing the description of typical grief. Critiques of Freud's grief work hypothesis have opened the doors to exploring alternative frameworks for considering the course and outcome of bereavement.

Over the last two decades bereavement theory and research have been informed by corollary fields of stress and trauma theories (Janoff-Bulman, 1989, 1992; Lazarus, 1999), attachment theory (Bowlby, 1980), and cognitive process models (Folkman, 2001; Nolen-Hoeksema, Parker, & Larson, 1994). While these have been helpful areas of inquiry, many feel that the complexity of the bereavement process necessitates its own research and theories (M. Stroebe & Schut, 2001a). M. Stroebe (2001) also argues that in these early days of bereavement research, a pluralistic approach may be necessary because of the complexity of bereavement. Three theories have emerged in the current literature that have been amenable to some preliminary research: The Two-Track model (Rubin, 1981), the Dual Process Model (Stroebe &

Schut, 1999), and the Meaning-reconstruction Model (Neimeyer, 1998). Each of these theories attempts to include some form of meaning-making in their models, however, Neimeyer's model is the only one that specifically focuses on the importance of meaning in bereavement. Neimeyer states that the central process of grieving is meaning reconstruction. To situate the current theoretical understanding of bereavement, I will briefly describe the three models with specific reference to each of the model's relationship to meaning-making.

Current Models of Bereavement

A. The Two-Track Model

Rubin's (1981, 1999) Two-Track Model of bereavement is the oldest of the three theories. It is also the only model that was based on the experiences of bereaved parents. This model was developed from the investigation of mothers who had lost children to SIDS (1981). The Two-Track Model attempts to describe both the process and the outcomes of loss. Its foundation is the psychodynamic model and the personality change model derived from stress and trauma research. These theories inform each of the two tracks which Rubin describes as multi-dimensional.

Conceptually, Track I, *Functioning* is related to the empirical literature on stress and trauma. It encompasses the person's ability to reestablish an adaptive response to life across a variety of areas (Rubin, Malkinson, & Witztum, 2000). The first track describes how people function naturally and how this functioning is affected by loss. Track I covers the areas of anxiety, depression, somatic problems, interpersonal relations, self-esteem, meaning structure, and investment in life. Meaning structure in Rubin's model describes the person's religious views, creating a somewhat limited

perspective on the area of meaning-making. Thus, Track I considers the person's affective, interpersonal, and somatic functioning as well as any psychiatric signs. Track II, *Relationship to the deceased*, is drawn from the psychodynamic perspective. It addresses how people maintain and also change their relationship to the deceased and has incorporated Freud's emphasis on relinquishing attachment to the deceased. Track II addresses the areas of affect towards the deceased, preoccupation with the loss, conflict, impact on self-perception, and memories and transformation of the deceased and the loss. Historically, these two tracks have been investigated independently but Rubin contends that the relationship between the two tracks changes with time.

Drawing from the psychodynamic literature, Rubin (1999) states that separating from the deceased is the "heart of the response to loss" (p. 683) and consequently, the goal of bereavement is the reorganization of the relationship to the deceased (Rubin et al., 2000). Therefore, with respect to meaning making, it is the person's religious views that may mediate the process of separation and reorganizing the relationship, but meaning making is not explicitly described in the process.

Following Freud's stage model, Rubin (1981, 1999) describes the merging and diverging of these two tracks. In the *Acute grief* period, the bereaved person must loosen his or her affective bond (Track II). This loosening is typically marked by significant changes in behaviour such as in familial relations and investment in life tasks, and changes in personality such as manifestations of anxiety, psychiatric symptoms, depression (Track I). Therefore, both affective detachment and the personality/behavioural changes are interwoven in the acute period. During the next

phase, the *Mourning period*, the process of detachment is less apparent and personality changes are less obvious. There is a gradual reinvestment in the relationship with the deceased. Consequently, the two tracks are interdependent yet are becoming independent from each other. In the final phase, *Resolution*, the individual has fully detached from the deceased and the personality changes have stabilized. Thus, the person can independently discuss the relationship to the deceased and any personality changes he/she experiences as a result of the death. The long-term effects of the loss can be realized.

Thus, the assumptions that undergird the Two-Track model are: 1) The experience of loss has a major impact on the bereaved. There is an expectation of return to pre-loss functioning at the very least, and the goal of bereavement is to reorganize one's relationship with the deceased; 2) Loss may be experienced as a trauma; 3) The initial challenge of bereavement is to accept the death of the loved one which sets in motion the change in relationship with the deceased; 4) As time goes on, there is less attention paid to reworking the relationship and functioning resumes to satisfactory levels; and, 5) A steady state is found in both functioning and attachment whereby investment in life, social supports, recollections of the deceased, and feelings created from talking/thinking about the loss become reasonably fixed. Thus, there is an implied endpoint.

Rubin encourages researchers to look beyond the bereaved person's overt functioning as a marker of grief resolution. He highlights the continuing relationship changes as a salient feature of adaptation to loss. One may speculate that in this process of negotiating the ongoing relationship with the deceased, the bereaved

person may review some deeply entrenched assumptions about being a parent, about what 'ought' to happen in life, and about his/her identity. However, Rubin does not bring this part of the stress and trauma literature into his model. Rubin et al. (2000) state that bereavement is a unique individual experience and to get a full understanding of one's experience, one would need to consider multiple variables including personal history, gender, culture, coping styles, personality traits, and support systems. This description of bereavement attests to the complexity of bereavement and why it can be a difficult experience to explain theoretically.

Rubin's model is useful in that it describes the more traditional features of bereavement that are often the focus of outcome research such as anxiety, depression, relationship to others, and overt functioning. But it also addresses another key, often overlooked, component which is the ongoing relationship with the deceased and its evolution over time. This feature is an important one for parental bereavement because of the complexity and powerful nature of the attachment. His work has also been substantiated in empirical studies (eg. Rubin, 1981, 1993; Rubin & Schechter, 1997).

Rubin (1993) found that parents who had lost a son in one of the two Israeli wars, were more anxious up to 13 years after the loss than non-bereaved parents. The bereaved parents also viewed their deceased sons in a more favourable way than non-bereaved parents. Thus, the emotional response and attachment continues for many years post loss. In trying to understand the perceptions of non-bereaved people towards the bereaved, Rubin and Schechter (1997) found that non-bereaved people felt that the bereaved person's outward functioning was an accurate indicator of how

the person was dealing with their grief. Therefore, if the person was still crying or was depressed, others would conclude that these outward manifestations provided an accurate gauge that the bereaved person was still grieving. This study underscores Rubin's contention that the supporter's ability to provide support is influenced by their perception of the bereaved person's overt functioning rather than making efforts at understanding some of the more covert manifestations of grief, such as the Track 2 features of ongoing attachment. Rubin (1999) warns that to focus solely on the outward functioning as a gauge of distress may result in many missed assessments and opportunities to provide support.

While Rubin does address meaning in the form of religious beliefs and attachments, he does not develop the concept of meaning. He agrees that the return to homeostatic functioning is the norm and this is not necessarily pre-loss functioning. However, there is no discussion about the process towards growth which can come about by re-working assumptions, values, beliefs and behaviours. Nor is there a description of the specific coping processes required (Stroebe & Schut, 1999).

There are some additional limitations to Rubin's model. Rubin (1981) states that the central process of grieving is a loosening of the attachment bond but later research summarized by Rubin & Malkinson (2001) found that parents of deceased children described their child in more idealistic ways than parents whose children were alive. Therefore, it may be better to describe the change in attachment as one that is "re-defined" or "symbolized" rather than loosened. Additionally, Rubin suggests that the attachment and cognitions and emotions become reasonably fixed. This suggests that there is some form of an endpoint rather than an ongoing reworking of the loss that is

informed by life's changes. Finally, Rubin's model retains some of the psychodynamic phase-model elements found in the earlier approaches to bereavement that may limit its capacity to investigate growth, benefit, and meaning.

B. The Dual Process Model

The Dual-Process Model (DPM) is not a phasal model but one that regards the process of bereavement as an oscillation between two types of stressors (M. Stroebe & Schut, 1999). This model is defined as "an attempt to integrate existing ideas found in related fields rather than an altogether new model" (M. Stroebe & Schut, 2001a, p. 394-95). In contrast to the Two-Track Model that is largely based on attachment theory, the DPM is regarded as more of an integrative model of bereavement. It was originated as an effort to understand coping with the death of a partner; however, no research is cited with respect to the development of the model.

M. Stroebe and Schut (2001a) argue that previous models of bereavement lacked definitions of stressors; thus, their model delineates two broad types of stressors: "loss-orientation" and "restoration orientation". Within each of these stressors they have situated bereavement relevant theories that have been developed in related fields.

The loss-orientation describes the person's concentration on, and dealing with, some part of the loss itself. Attachment theory would provide one theoretical foundation for this stressor as would Freud's theory of grief work described above. Thus, experiences of rumination, replaying the circumstances of the death, yearning, and emotional responses such as crying are all part of this orientation. Consequently, one would expect negative affect to predominate in the beginning and with time,

positive emotions would begin to take hold. Because this model is not a phasal model, the emotional experiences are seen as waxing and waning over time. They expect that the loss orientation will tend to dominate early on in the bereavement (M. Stroebe & Schut, 1999). However, as some of the outcome research shows, parents describe and report negative affect and symptoms for a minimum of two years post loss (Murphy, Johnson, Wu, Fan, & Lohan, 2003; Ott & Lueger, 2002). This suggests that more research needs to investigate the loss orientation in bereaved parents to help understand norms for this group. While bereaved people are negotiating the stressors in the loss orientation, Stroebe and Schut allude that there is a potential for finding meaning. As one oscillates between approach and avoidance of the loss and resultant feelings, meaning is being created. This will be discussed further below.

The restoration-orientation is seen as an aspect of loss that has not been developed in the literature as much as loss-orientation. This stressor refers to the consequences of bereavement, primarily seen as secondary losses. Secondary losses are regarded as losses that come about as a result of the direct loss, and how these losses are handled. For example, a secondary loss may be that the parent no longer feels that they can participate in Parent Teacher Association meetings due to the death of their child. In this example, the parent may ask if they could participate in some other way. Thus, the restoration is not about the outcome, such as feeling that they are still a contributing member to the school, but it is about the process in which the bereaved person engages in order to adjust to the significant changes created by the death. Themes that are pertinent to restoration-orientation include mastering tasks originally assumed by the deceased, re-defining an identity, and dealing with living

arrangements that may now be different (M. Stroebe & Schut, 1999). The secondary stressors generated for bereaved parents would undoubtedly be different than those described for widows(ers) but this has not been investigated.

The second aspect to their model is the oscillation that occurs between these two orientations. What makes their model unique is this dynamic fluctuation between the two stressors rather than the phase-based models that had dominated bereavement theory previously. They propose that the bereaved person will oscillate between and within the loss- and restoration-orientations. For example, the individual will periodically confront emotional aspects of the loss, and at other times, will avoid or deny them in favour of restoration-orientation related activities.

The final aspect to their model refers to the cognitive processes in the bereavement experience. Drawing from the cognitive process models (eg. Folkman, 2001), they describe the meanings, assumptions, and types of expression that are reflected in good versus poor adaptation (M. Stroebe & Schut, 2001b). Thus, the oscillation that occurs is a confrontation-avoidance dynamic. The oscillation occurs between positive- and negative- affect (re) appraisal, and between positive- and negative appraisal. For example, grief is heightened when negative affect such as sadness dominates. However, working through it, which includes rumination can be helpful in coming to terms with the loss. Conversely, positive reappraisals sustain the coping effort giving it meaning. However, if these positive appraisals are done relentlessly, grieving is denied. The authors suggest that this cognitive oscillation helps explain the meaning systems or narratives created by the bereaved person. M. Stroebe and Schut (2001a) have included rumination and positive reappraisal in an

effort to address the meaning process in bereavement. Therefore, while meaning is not a focus in the model, they suggest that meaning-making can occur and the oscillatory process explains *how* the bereaved person comes to find meaning. They view meanings as cognitive expressions (Stroebe & Schut, 2001b) that are associated with good versus bad outcomes. Implicit in their theory is that the meanings created are cognitive and are logically constructed. This approach then does not address the spiritual, emotional and tacit aspects to the creation of meaning. These facets will be discussed in the Meaning-Reconstruction model below.

M. Stroebe and Schut (2001a) agree that their model needs to be researched further to investigate its applicability to the variety of loss experiences and the variety of individual differences. Their model is useful in that it includes secondary losses as a critical aspect to bereavement. It confirms that denial is necessary and beneficial. And, it does not prescribe a course of bereavement but an oscillatory process that allows for individual differences. They do not focus specifically on meaning-making; however, they note that the avoidance-confrontation oscillation facilitates the individual's creation of meaning. Therefore, both the Two-Track model and the DPM include some aspect of Freud's grief work theory. The Two-Track states that the goal of bereavement is to relinquish attachment, while the DPM includes the emotional expression of grief as a key aspect to the loss-orientation stressor. Each emphasizes a new aspect to bereavement theory. The Two-Track addresses the ongoing relationship with the deceased while the DPM includes secondary losses as an important aspect to negotiating bereavement.

C. The Meaning-reconstruction Model

Neimeyer's model has its roots in constructivism (Neimeyer, 2001a). Stroebe and Schut (2001a) describe this approach as one of the most significant developments in the study of bereavement. Fundamental to this model is that the relationship to the deceased is actively explored and re-defined over time, thus, it is never complete. This is in direct contrast to the Two-Track Model. Because he views humans as "inveterate meaning makers" (Neimeyer, 2000, p. 200), these constructions are created through narrative and are affected by the bereaved person's personal, familial, and cultural experience (Neimeyer, Prigerson, & Davies, 2002). Individuals create unique systems of meaning which are arranged around core assumptions. These systems of assumptions dictate behaviour and perceptions. Generally these meaning systems are internally consistent, but are also supported by the culture and provide some security for operating in the world. Consequently, if an experience does not fit into one's schema then this will be experienced as problematic. Thus, when a loved one dies suddenly, unexpectedly or at a young age, the schemas or assumptions are threatened so one must engage in a process of rebuilding. By extension then, meaning reconstruction is viewed as the *central* process of grieving (Neimeyer, 1998).

The meaning-reconstruction model in general, rests on a number of assumptions (Neimeyer, 2001a). The first assumption is the *narrative truth*. This truth means that there is not an identifiable, external reality that is "true" or "correct", but only one that is created and defined by the individual construction. Therefore, the inclination for storytelling is one way in which we construct and make sense of our lives. Thus,

these narrative truths are more important than some 'objective' truth because they reflect an effort towards making sense and creating a meaningful story of our lives.

The second aspect to this model is *discourse and rhetoric*. For a narrative to make sense, individuals must draw upon a discourse that is recognized and understood by them and the culture. This is akin to Marris' (1974) theory about loss whereby a loss and any aspect of it can only be integrated into what is already known, before it can become something new. Some of the previous discursive frameworks have understood grief as a disorder that unfolds in a series of stages. The constructivist stance is that each person constructs his/her own discourse that is rooted in family, culture, religion etc. and these individual features provide some understanding for how the loss will be accommodated into the new identity. Embedded in this perspective is that the person is an active participant in responding to the death, not a passive reactor (Neimeyer, 2000; Neimeyer, Keesee, & Fortner, 2000).

The third feature of this model describes the *tacit* dimension that is part of language. In other cognitive accounts of meaning-making such as the DPM, there is an assumption that the process of finding meaning is a logical, articulated process; however, Neimeyer (2000) argues that many of our constructions of reality are verbally inexpressible and thus, are not amenable to logical articulation.

The fourth aspect is the *relational self*. This refers to how one defines oneself. The self-narrative is constantly changing across situations, time, and people. Thus, our self-narrative will be filled with contradictions, fragmentation, and tension which in this view, is not necessarily something that needs resolution. Instead, this tension

can be the catalyst for opening up an internal story to something new and more complex. Therefore, once bereaved, one must find others who are willing to validate an emerging and/or new identity. Neimeyer suggests that ironically, this person may be the one who died.

The final concept is *evolutionary epistemology*. In this context, it means that the self-narrative changes across time and contexts. Thus, after loss, the bereaved person may experiment with new ways of being, new identities, and behaving, until something feels comfortable. These experiments open the door to experiencing growth in various aspects of the self. Meaning reconstruction is not just about the outcome or some desirable goal but it is also about the process and activity of finding the meaning (Neimeyer, 2000).

Applying the constructivist position to grief theory, Neimeyer et al. (2000) offers 6 propositions: 1) Death can validate/invalidate the constructions we have or it may be an experience for which we have no constructions. Therefore, one can ask, does a particular death coincide with my current assumptions?; 2) Grief is an idiosyncratic, intimate experience that is intimately tied to who we are. This relates to the self-narrative. Thus, one is faced with asking who we are in light of this loss; 3) Grieving is something we do, not something that is done to us. Neimeyer highlights that there are always choices in how to respond such as to deny or to actively engage in “grief work”; 4) Grieving is an act of either affirming or reconstructing a personal world of meaning that has been created by the loss. This process involves the narrative and the necessity of the “other” for validation; 5) Feelings have functions and can be regarded as signals of efforts toward making meaning. Instead of regarding feelings as only

symptoms of distress or pathology with a goal to ameliorate, constructivists view emotions as vital expressions towards the meaning making effort because they represent processes that are difficult to otherwise observe; 6) Identities continue to be reconstructed in negotiation with others. Therefore, while loss is an individual and personal experience, it is also one that is situated in a larger social sphere.

The meaning-reconstruction approach views significant events such as loss, as opportunities for growth. The process by which one can experience growth means re-learning the world that had been taken for granted. Areas that need to be re-learned are our physical surroundings, our social surroundings, ourselves, and our relationship to the person who died (Attig, 2001). The meaning created evolves over time and is person, time, and situation dependent. Therefore, the meaning that has been made was probably not available at an earlier point in grief because of the constellation of these features (Neimeyer et al., 2000).

The meaning-reconstruction model is the only model of the three that specifically focuses on the creation of meaning. It highlights how individuals uniquely construct meanings from life events. An individual will feel compelled to find meaning when the event challenges deeply held beliefs, values, and assumptions. Consequently, this model appears to be uniquely suited to the investigation of parental bereavement. A significant limitation to this model is the lack of research specifically testing it. There has been growing research showing that people create meaning after loss (Frantz, Farrell, & Trolley, 2001; Hogan & Schmidt, 2002; Janoff-Bulman, 1989; Janoff-Bulman & Frantz, 1997; Richards, 2001; Taylor, Kemeny, Reed, Bower, &

Gruenewald, 2000); however, there seems to be no research specifically addressing the model.

Table 1 provides an overview of the above models noting their respective theoretical orientations, goals, outcomes, and approach to meaning in bereavement. Therefore, while the above models share some theoretical foundations, their focus on process, outcome, and the significance of meaning-making differ. These differences result in the way researchers investigate the process and outcome of bereavement.

As was mentioned above, historically, researchers have focused on the negative outcomes of grief. Yet more recently, researchers are realizing that grief is far more complex than the stereotypic responses of sadness, anger, anxiety, and fear. Some empirical work is also investigating some of the more ‘positive’ experiences of those who are bereaved. However, one of the biggest limitations in the field of bereavement is the lack of communication between researchers and theoreticians. And of the above models, only the Dual Process Model and the Meaning-reconstruction model provide a framework for the range of positive and negative emotions and cognitions that may contribute to the process of meaning-making. The following section will provide an overview of research done in child loss with a focus on studies that included meaning.

Table 1***Summary of Theoretical Models of Bereavement***

	Theoretical Foundation	Goal	Outcome	Meaning-Making
Two-track (Rubin)	Psychodynamic (Track 1) Stress & Trauma (Track 2)	Reorganization of relationship to deceased	Return to pre-loss functioning- investment in life, social supports, discussion of deceased all now essentially fixed Mourning may go on after changes in personality have stabilized and personality changes may be ongoing past the time when bereaved has relinquished attachment	Situated in religious beliefs
Dual Process (Stroebe & Schut)	-Cognitive Stress theory -Cognitive Process Models (eg Folkman) -Attachment Theory	-“come to terms with the loss” - not specifically defined	- not stated clearly but adaptive coping requires an oscillation between positive and negative appraisals in the loss and restoration orientations	- the cognitive process of oscillation helps to explain the meaning systems - acknowledges importance of meaning construction
Meaning- reconstruction (Neimeyer)	- Constructivism - some relationships to Janoff-Bulman’s theory of shattered assumptions	- meaning reconstruction - relearn world - come to terms with anguish	- relearn physical, social surroundings, self, and relationship to deceased - ongoing; it is an activity more than an outcome	- not a logical, verbalized process - meanings are arranged around core assumptions- dictate behaviour and perceptions - when an experience does not fit into our schema, it creates tension

Empirical Studies in Parental Bereavement

Outcomes of Bereavement

Research on parents who have lost a child has investigated a number of the traditional areas including depression (Davis, Nolen-Hoeksema, & Larson, 1998; Lehman, Wortman, & Williams, 1987; Lepore, Silver, Wortman, & Wayment, 1996; Volker & Striegel, 1994-95; Znoj & Keller, 2002). Generally, mothers tend to report experiencing more depression than fathers. Parents are more depressed than the general population, and this depression can be felt for years after the death. This long-lasting experience of depression is evidence that parents do not return to 'normal' as defined by grief work. Another traditional area of investigation, are the physical effects and increased mortality rates post-death. Parents generally experience a decline in physical health (Rando, 1983, 1991; Znoj & Keller, 2002) and there is an increase in mortality (Lehman et al., 1987). Thus, the traditional outcome measures have provided evidence that parental grief results in some of the generally expected grief responses.

However, a number of researchers propose that parental loss is unique and worthy of independent investigation (de Vries, Dalla Lana, & Falck, 1994; Leahy, 1992-93; Rando, 1983; Volker & Striegel, 1994-95; Znoj & Keller, 2002). It is hypothesized that because of the complexity and depth of attachment and the numerous assumptions embedded in the parent-child relationship, that this loss is "life's greatest tragedy" (Brown, cited in de Vries et al.). Thus, the dominant areas of inquiry in parental bereavement reflect this view. Areas of inquiry in parental

loss include coping responses, attachment bonds, and subsequent relationships with spouse, family, and friends.

The emotional coping responses investigated most frequently in parental bereavement include self-blame, rumination, and guilt. Rando (1983) found that mothers who were highly involved in their child's hospitalizations were more likely to ruminate. She concluded that as participatory behaviours in hospital increased, the more likely a mother was to get "wrapped up" in her child's illness and care, thus, neglecting other aspects of her life. Sanders (1982-83), in comparing sudden death and chronic illness, found that those caregivers who experienced a long-term illness prior to the death of their loved one were more likely to ruminate. And Bohannon (1990-91) and Nolen-Hoeksema et al. (1994) found that females were more likely to ruminate than males. Thus, rumination may be found more in women and in those bereaved after caring for a child who had a long-term terminal illness. Guilt is reported by parents, specifically mothers in response to the death of their child. Comparing mothers to widows, Leahy (1992-93) found that mothers experienced significantly more guilt, sadness, social withdrawal and self-image changes than widows. In another comparative study, this time on child loss by suicide, accident, or chronic disease, guilt was experienced by all parents, but with parents of children who committed suicide experiencing the most guilt (Miles & Demi, 1991-92). Shanfield, Swain, & Benjamin (1986-87) found that parents who lost a child in an accident felt more guilt than parents whose adult children died from cancer. Guilt seems to stem from the parents' belief that it is their duty to protect the child and the child's death indicates they failed as a parent. These

studies underscore the assumption that regardless of the age of the child, parents should be able to protect their child from adversity.

Cognitive coping in the form of intrusive thoughts and defense mechanisms such as denial and avoidance is another area explored in child loss research. Lepore et al. (1996) found that both mothers and fathers experienced equally intrusive thoughts; however, mothers and fathers expressed them very differently. If mothers felt that they were in a socially unconstrained environment, then they fared better long-term; however, if they perceived that their environment was not responsive to their need to talk, then they experienced greater levels of depression. Because the authors view intrusive thoughts as representing unresolved traumas, and the permission to speak an opportunity to resolve these traumas, one is left questioning how fathers deal with their intrusive thoughts. This study underscores how the environment can help or hinder a bereaved parent's coping.

Hogan and Schmidt (2002), using Structural Equation Modelling, found that once the parent experiences intrusive thoughts, feelings, and images, they cope by making efforts towards social support and then personal growth. One limitation of the study was that the sample was primarily female, thus potentially skewing the perceived benefit of or need for, social support. However, as Miles and Demi (1991-92) found, loneliness is the most distressing experience in parental bereavement, thus, social support may be difficult to receive and seek. As Hogan and Schmidt have described, making the effort towards connecting with others or being able to receive others comes at a critical turning point during the avoidance of the feelings, thoughts, and images. This connection to others can shift the person

out of intrusive thoughts and into a new way of processing their loss which includes confrontation. The area of social support is one that is complex and provides conflicting evidence. Some research such as the findings of Hogan and Schmidt, demonstrates the effectiveness of social support, while other research (eg. W. Stroebe, Stroebe, Abadumkin, & Schut, 1996) challenges how well social support can ameliorate grief symptoms. W. Stroebe et al.'s study suggests that for spousal loss, social support does not provide a buffering effect against loneliness. Social support will be discussed further below.

Denial and avoidance are evident earlier in the coping response and act as the buffer to intrusive thoughts. Janoff-Bulman (1989) suggests that the negotiation between denial and intrusiveness reflects the individual's efforts towards accommodating the new experience into old assumptions. Her theory is particularly relevant for child loss because it addresses the shattering of assumptions. In child loss, there are many assumptions that are destroyed such as a child should not die before a parent; a child represents the future; a parent should be able to protect the child; and a child is innocent and should not suffer. Consequently, the parent is faced with the task of re-building a world that undoubtedly had more fundamental assumptions shattered than any other loss.

A final consideration in looking at the outcome literature is the time since loss. Many researchers include either a very limited time span, usually up to two years post-loss, or there is little control for the post-loss time span. Undoubtedly, one of the contributing factors to this problem is the accessibility to a study population. In a recent article focusing on child loss (though the focus was on

sudden violent death), the researchers found that 70% of parents sampled reported that it took 3-4 years to put their child's death in some perspective and to be able to move on with their lives (Murphy et al., 2003). Therefore, in terms of investigating the process of finding meaning, this research suggests that a sample that includes parents whose child died at least 3 years ago, may be the most 'informed' about their experience and process of finding meaning.

A final area of inquiry into bereavement is the effect that social support has on the bereaved person's experience.

Social Support

The term "social support" emerged in the 1970s (Williams, Barclay, & Schmied, 2004) and since that time has been explicitly defined in a variety of ways or implicitly understood in research. Sarason, Levine, Basham, & Sarason (1983) have defined social support as "the existence or availability of people on whom we can rely, people who let us know that they care about, value, and love us." (p. 127). Their definition underscores two basic elements: a) there are a sufficient number of people available to turn to in times of need, and b) there is some evaluation of the satisfaction with that support. With respect to bereavement, support may be considered from a personal resource perspective and a professional resource perspective. Vachon and Stylianos (1988) state that "bereavement is a social network crisis" (p. 175). This statement emphasizes that bereavement is not just a solitary experience but one that is shared with others. Bereavement research that includes a social support measure most often finds a positive correlation with bereavement "recovery" and positive social support. Bereavement recovery has

been measured in a variety of ways such as depression (Moskowitz, Folkman, & Acree, 2003), distress (Nolen-Hoeksema & Davis, 1999; Vachon, Sheldon et al. 1982; 1988) (see M. Stroebe, W. Stroebe, Schut, Zech, & van den Bout, 2002 for a challenge to this relationship), and PTSD (Murphy, Johnson, Chung et al., 2003). However, as noted above there may be some other factors affecting social support, for example, ruminators are more likely to seek social support (Nolen-Hoeksema & Davis), gender, such that women are more likely to seek support (Suiter & Pillemer, 2000), and availability of a non-constraining environment (Lepore et al., 1996). These studies have focused largely on the personal network of the bereaved individual.

Given that personal supports may eventually fail for various reasons, such as tiring of hearing the same stories, wanting the individual to “get better”, or the family is also grieving, bereaved individuals may seek support through professional avenues such as through a bereavement support group or one-on-one therapy. Murphy, Johnson, Lohan et al. (2002) provide a clue as to who may feel the need to join a support group or seek professional help when personal resources fail. They found that bereaved parents who scored higher in PTSD and distress were more likely to join a support group. When parents were asked to recall 5 years after the sudden death of their child what factors most helped them in their bereavement, support group attendance was one of the top three factors (faith and study participation were the other two factors). In a related article, Murphy, Johnson, and Lohan (2003) found that parents who attended a support group were four times more likely to find meaning than parents who did not attend a support group.

Neimeyer (2000) in a review of the literature between 1975 and 1998 confirmed that grief counseling may be the most effective mitigating variable for those traumatically bereaved. He defined the loss of child as a traumatic loss. However, of some consideration is Jordan and Neimeyer's (2003) review of grief counselling studies that conclude that the overall efficacy of grief counselling is low. They provide three explanations for why the results may be skewed. The first explanation is that those who seek counselling may be a higher-distress group than those who found more personal means for coping with their loss. The second explanation is that the studies reviewed may have employed too weak a treatment to provide any measurable effect. Additionally, the timing of the intervention may be a factor as some research suggests that negative feelings in the second year and third year of bereavement worsen (Wortman & Silver, 2001). Thus, a few sessions during this time probably would not have much effect in ameliorating the more commonly measured negative symptoms. Related to this is the composition of the group which may focus on the needs of a particular bereaved group, such as a group whose loved one died as a result of suicide, to the exclusion of others. This would relate to Stroebe and Schut's Dual Process Model (1999) description of restoration-orientation themes whereby the uniqueness of the loss creates specific challenges to new identities and roles. This is also consistent with research by Klass (1984-85) and Geron, Ginzburg, and Solomon (2003), who found that being validated and normalized were one of the key features of participating in a support group. Thus, participating in a group of similarly bereaved may provide better suited role models, and validation.

The final explanation provided by Jordan and Neimeyer (2003) for the low support group results relates to methodological problems. Specifically, the studies tend to lack control groups, lack random assignment, have no clear theoretical foundation, and have a small sample size. The absence of theoretical base is another example of the field in general, in which theory and practice/research are not interwoven. As a result of these methodological problems, it is distinctly possible that the wrong outcomes are being measured. The outcome measures largely focus on the negative sequelae of depression and anxiety among others, to the exclusion of potentially positive outcomes of growth.

Summary of the Empirical Literature

The empirical literature has traditionally focused on the negative sequelae of loss. Research has focused more on spousal loss with an assumption that this loss is representative of all losses. Research that has included comparative samples of bereaved spouses and parents or bereaved individuals from a variety of sudden or illness-related causes has shown that the outcomes of loss are different. Therefore, a focus on a more homogeneous group may help to investigate the unique bereavement experiences. Another problem in the bereavement literature is the paucity of linkages between theory and research. Few studies have attempted to test the theories proposed. Because bereavement is so complex, research that is linked to theory would help elucidate the myriad of variables that affect the bereavement process and outcome.

The empirical literature now acknowledges that bereavement can and should include both positive and negative outcomes (Bonanno, 2004). However, little

attention has been given to the process in which people engage meaning-making. Additionally, there have been a variety of overt and covert definitions of meaning. Earlier on in the literature, there were two primary problems when studying meaning. First, the definition was implicit and suggested a definition of making sense, such that the event fit with pre-existing schemas or assumptions. The second problem was that the two definitions of making sense or benefit-finding were lumped together (Lehman et al., 1987; McIntosh, Silver, & Wortman, 1993), thus, hampering an understanding of what the participants meant by finding meaning.

Meaning-Making

Viktor Frankl propelled the concept of meaning into psychological discourse and into therapy through his logotherapy. Frankl's seminal works (1959, 1969, 2000) proposed that we have a 'will to meaning'. He stated that meaning fulfillment can be found through three avenues (2000): a) by doing a deed or creating something; b) by experiencing something or encountering another person; and most relevant to this project, c) facing a fate that is unchangeable. Frankl's conception of meaning is a spiritual one and is represented by questions like "Why me?" Since then, the concept of meaning has been extended beyond Frankl's more philosophical explorations (Wong, 1998) and has also been pursued through empirical research (Calhoun & Tedeschi, 2001; Gamino & Sewell, 2004). Davis, Wortman, Lehman, & Silver (2000) proposed two circumstances under which a person will struggle to find meaning. The first instance occurs when the event shatters the person's view of the world. For example, when a healthy athletic person dies suddenly of a heart attack, one may question the fairness of the death because

the individual seemed to do everything 'right'. Second, when the relationship is defined as a significant one by the bereaved person, meaning efforts will be made. For example, when a loved one dies with whom we had a dependent or inter-dependent, loving relationship we will undoubtedly struggle to re-define ourselves without that person and re-define our purpose in light of the loss. Both the assumptions shattered and the significance of the relationship are highly salient for a parent who loses his/her child.

Davis et al. (1998) propose a theory that meaning-making has two components that follow different processes: making sense and benefiting. When a parent can fit the loss of their child into their pre-existing assumptions which the authors define as making sense, they do so early on and report good adjustment 6-months post-loss. However, for parents who could not make sense of the death, they reconstructed the loss in terms of finding some benefit. Those parents who could find benefit were better adjusted 18 months post-loss. Thus, making sense could be defined as the default response and when that cannot happen, finding benefit provides some form of compensatory response that allows for a re-building of assumptions (Davis, 2001). Yet as Davis et al. (2000) state, there needs to be a more precise definition of what kind of 'meaning' is being investigated. Because I have assumed that the loss of a child in the 21st century in Canada shatters assumptions and asks the parent to either assimilate or accommodate the loss, the focus on meaning will be on perceived benefit, growth, and sense of purpose (Davis et al., 2000). Davis (2001) suggests that the critical distinction between making sense or meaning-as-comprehensibility (Janoff-Bulman & Frantz, 1997) and finding

benefit or meaning-as-significance, has to do with what is shattered. He suggests that one can make sense when one's *worldviews* have been threatened; however, one searches for benefit when one's *self* is threatened. Thus, one may speculate that the loss of a child is dually shattering, both to worldviews and to self. But it is the shattering of what it personally means to be a parent, the dreams for the child, the perceived parental omnipotence, and personal dreams for the self as a parent, which may necessitate a search for meaning.

In creating meaning one may encounter it either through *making meaning* or *finding meaning* (Attig, 2001). *Making* meaning involves a deliberate, conscious, active effort to bring new meanings into our life. *Finding* meaning involves a receptive awareness of experiences, meanings, and actions. In this stance, the bereaved person gains a better appreciation for the familiar and accepts meanings that can occur spontaneously. Both these processes relate to Neimeyer et al.'s (2000) concept of meaning-making wherein the bereaved person is an active participant in the grief. Consequently, the bereaved person is consciously seeking and receiving information for potential assimilation into the new schemas. Therefore, I will distinguish these two processes such that when a person is finding meaning, they are receptively engaged in the environment while making meaning refers to a more conscious active engagement with the environment. However, the term meaning-making will be used more generally and can encompass both these processes. Because earlier research suggests that those who find benefit are better off in the long term, then it behooves the profession to investigate this more thoroughly. Thus, an exploration into this process would be an important

contribution in the field of bereavement.

Bereavement does not end after the more commonly researched time intervals of one or two years; it unfolds over years (Neimeyer, 2001a). Yet what exactly unfolds over time is not wholly clear. For the few studies that have followed bereaved persons over several years, the question related to meaning has been confined to usually a single item question (Lehman et al., 1993; Murphy, Johnson, & Clark, 2003). These studies usually ask whether the person has found any meaning or made any sense of the death as the only data source for meaning. These studies are helpful in that they follow participants for many years; however, one question that constitutes the process of meaning is insufficient for its complexity.

There have been some recent developments which address both the necessity of considering a longer interval since death when investigating meaning, and some of the factors that contribute to finding meaning. Ott and Lueger (2002) found in a prospective study following widows over the first two years after the death of their spouse, that a composite mental health score (subjective well-being, psychiatric symptoms, and current life functioning) of bereaved persons never reached the scores of the nonpatient population. This research indicates that the capacity to find meaning may take longer than the commonly used 2-year follow-up time that bereaved participants are tested or interviewed. This finding is consistent with Davis et al.'s (1998) study whereby time since death was positively related to growth. In another study, using a sample from an Organ Tissue donation agency, Hogan & Schmidt (2002) tested three possible paths representing the bereavement process. There was partial support for the Dual Process Model but the path with the

best fit followed the course of first experiencing despair and detachment which was followed by intrusive thoughts, which led to avoidance of those thoughts, followed by social support, and then growth. Some limitations to this study were the mixed population (though most were parents), and the primary sudden/violent nature of the death (accident, suicide and homicide) and the cross-sectional data. An advantage to the study was that the average time since death was 4 years, which may contribute to why some growth was described; however, the specific nature of the growth was not described. Thus, it appears that some of the more recent studies are trying to link empirical studies with both process and theory.

While some researchers are beginning to look at the process of meaning-making, more have described the meaning outcomes of bereaved individuals. The more commonly reported meaning outcomes include spiritual growth (Richards, 2001), enhanced personal relationships (Frantz, et al., 2001; Richards, 2001; Tedeschi, Park, & Calhoun, 1998), feeling more self-reliant and self-confident (Folkman & Moskowitz, 2000; Frantz et al., 2001), greater self-knowledge (Janoff-Bulman, 1989), re-ordering priorities (Taylor et al., 2000), and a sense of wisdom (Janoff-Bulman & Frantz, 1997).

The research into child loss seems to be venturing a bit further from the traditional outcomes. Researchers are only beginning to include meaning-making in their outcome studies and as has been described above, most of the previous outcome studies have focused on the negative outcomes of bereavement. Focusing on meaning making is not done at the exclusion of the expected grief experience, but worthy of exploring *in addition to* those grief symptoms. Research into the

pursuit of meaning has found that many parents engage in some sort of search (Uren & Wastell, 2002).

Rationale for Research

The focus of bereavement literature has been on normative losses such as late-life spousal loss with little attention to bereaved parents whose child died of illness. Some previous research suggests that there may be unique experiences in bereaved parents yet the focus has been more on the traditional areas such as health, mortality, and psychological outcomes such as heightened depression.

As noted above, researchers in the area of bereavement are only recently beginning to understand its complexity. One of the primary areas of research that is emerging includes meaning-making. Some research has investigated the meaning outcomes of bereaved individuals, but very little has documented the process of meaning-making. Empirical research suggests some concepts that have some relation to meaning-making such as time since death, and the availability and satisfaction with social support; however, how these factors evolve over time to help or hinder the process is not documented and is thus, unclear. I sought to understand this complex process of bereavement and meaning-making over the course of time.

Research Questions

Creswell (2003) suggests that the characteristic of good qualitative research focuses on a single phenomenon. The single phenomenon of this study is the process of bereavement in parents. Therefore, my grand tour (Werner & Schoepfle, 1987) and sub-questions related to this inquiry were as follows:

How do parents describe their bereavement experience since their loss?

The sub-questions that further guided my inquiry were:

- a) Do parents describe finding meaning/benefit/growth/purpose after the loss of their child, and if so, how?*
- b) What are the meaning outcomes defined by the parents?*
- c) During the course of bereavement, what is the role of social support?*

It should be noted that the original design of this study had included a mixed methods approach due to the interdisciplinary nature of my academic programme. My plan was to recruit participants through the assistance of bereavement support groups. Additionally, I had intended to access potential study participants through an on-line version of the questionnaires which was also linked to the web-sites of the various bereavement groups with which I had liaised. The intent of the questionnaires was to explore concepts related to the effect of time on growth, and the relationship between social support and neuroticism on measures of grief and growth. Further, it was my hope that parents interested in being interviewed might emerge and so the survey was an approach used to identify study participants for the qualitative exploration. Finally, the questionnaires were included as a method of triangulated inquiry. While I had originally hoped to obtain a larger sample of parents interested in completing the survey, a sufficient sample for prediction was not met. As such, this thesis focuses on the qualitative inquiry only, particularly as the central phenomenon of the process of meaning-making was explored in greater depth through the qualitative interviews with parents bereaved by illness. (Note: A summary of the quantitative findings can be found in Appendix A.)

METHODOLOGY

Participants

Participants for the inquiry were bereaved parents. As previously discussed some research has shown that the type of death -- sudden or anticipated -- results in different bereavement experiences. Therefore, given the potential for unique experiences as a result of the type of death, a more homogeneous sample by type of death was defined. All of the children of the study's participants died from an illness that lasted a minimum of six months. By choosing six months for the length of the illness, I was hoping to minimize a parent's perception that the death was sudden. As well, the broad time span was chosen to allow for a greater range in experience and the possible evolution of meaning-making.

Therefore, the selection criteria for participation were: a) parents who lost a child who was under the age of 25 and who was living at home; b) the child died from an illness that lasted a minimum of 6 months; c) the child's death occurred between 6 months and 20 years ago. The primary reason for selecting these criteria was to ensure that there was some commonality in the sample of participants. However, there was heterogeneity in the length of time since the death.

The sample included 16 parents. Six parents had been bereaved between six months and five years, six parents had been bereaved between six and ten years, and four parents had been bereaved for more than ten years. The total parent sample consisted of 13 women and three men. Nine women and two men participated in face-to-face interviews and two women wrote their answers to the

interview questions. The remaining three parents, two mothers and one father, wrote their answers to the questions posed in the first questionnaire only (Appendix C). Comparison of the group who participated in the interview and those who did not participate yielded no significant differences in any of the demographic measures. The age range of the parents was 36 to 68 years. Parents had been bereaved between 2.22 and 17.98 years. All parents were Caucasian and were employed full-time or part-time.

Thirteen of the parents were married. Two couples participated. Nine married parents participated but their spouse did not. Of the remaining parents, two were unmarried and one was widowed. Of the married sample, 10 parents were still married to the parent of the deceased child.

Four parents had at least one child younger than the child who died, not necessarily born subsequent to the death. Fourteen parents had other children than the child who died and two parents were now without a living child. Twelve parents had achieved post secondary education with a range of high school to graduate school.

The age range of the child when she/he died was between 1 and 22 years of age. The majority of children died from cancer. Seven of the children experienced a remission and relapse during the course of their disease. I mention this as during my professional work as an art therapist, I had observed that remission and relapses often created an experience that parents used to describe to me as a “roller-coaster”. The remaining illnesses included neurologic, hematologic, and genetic diseases.

Eleven parents came from Southern Ontario with seven of those parents from larger urban centres and the remaining four parents from rural Southern Ontario. A further three parents came from mid-size urban centres in Eastern Ontario, and the remaining two parents were from British Columbia.

Recruitment

In an effort to reach the greatest number of potential participants, a number of strategies were employed to notify parents of the study. The first recruitment strategy was via personal communication. Because of my previous work at a large children's hospital as an art therapist for seven years, I had maintained contact with some families that I had worked with over the years. I informed these parents about my study and asked if they would be willing to advise other parents about the study. As such, I was employing a qualitative recruitment technique called snowballing (Patton, 2002). Because I was interested in meaning-making, which not all parents experience, snowballing is a very effective technique for recruitment. A total of 5 parents participated as a result of my personal contacts and of these parents, three participated in an interview.

The second recruitment strategy that I employed was to work through existing bereavement and oncology parent support organizations across Ontario. In qualitative research, gatekeepers are often used to assist researchers in entering the field and gaining access to study participants (Berg, 2001). Therefore, I contacted the head of bereavement and oncology parent support organizations across Ontario and inquired whether the organization would be willing to notify their member-families of my study. Consent was obtained either through a presentation to the

Board or through a written submission to the Board. All groups who were approached agreed to notify their parents of the study. Upon consent, notifications were posted on websites and in newsletters (see Appendix B) and ran for approximately 8 months. This method of recruitment garnered 10 parents. Finally, a webpage was created for the study and was linked to one other bereavement support group site. Further, the webpage was also part of the website for Concordia's Centre for Research in Human Development but it was unlikely that a non-bereaved person would have found this webpage just by 'surfing'. This web page described the study and provided an on-line format of the questionnaires. Additionally the web page allowed parents to notify me if they wished to participate in the interview provided they live in Ontario or Quebec and spoke English. One parent filled out the web-based questionnaires with no follow-up for interview. Therefore, it cannot be determined how this parent came to know about the study. Altogether, four parents contacted me through email indicating their interest in participating.

Data collection occurred between July 2003 and February 2004. I continued my data collection efforts until I believed that saturation of the data had been determined (Glaser & Strauss, 1967). When all the data collection and sources of information were complete and no new data was emerging, I considered the process to be complete.

All parents were asked to fill out the questionnaires (See Appendices H, I, J) with the understanding that the qualitative interview was optional. Of the 16 parents who completed the questionnaires, 11 participated in a face-to-face

interview, two wrote their answers to the interview questions, and three participated in the questionnaire portion only. It should be noted that the two parents who wrote their answers to the interview questions lived outside the geographic boundary.

These parents volunteered to write their answers to the interview questions.

Additional qualitative data were collected on the full sample of 16 parents through the first questionnaire. This questionnaire included an abbreviated version (6 questions) (Appendix C) of the interview.

Qualitative Data Collection

Interview Schedule Development

The data were collected using a narrative approach. Fraser (2004) states that storytelling is now regarded as a valid approach in the understanding of how people construct and produce knowledge. Fraser goes on to say that “with the capacity to recognize people’s strengths and engage people in active, meaning-making dialogues, narrative approaches... may help... move to more generally explore social phenomena” (p. 181). Narrative inquiry assumes that people live “storied lives” and that by telling and retelling our lives, we are better able to make sense of it (Marshall & Rossman, 1999; Ollerenshaw & Creswell, 2002). The principle property of narrative inquiry is its “sequentiality” in time. The story involves unique individuals, events, and psychological states (Bruner, 1990; Riessman, 1993).

Ollerenshaw and Creswell (2002) propose that there are several common characteristics to narrative inquiry. The researcher emphasizes learning from the participants, and this learning is done through the stories told by the individuals

involved. It is the stories that constitute the data. These data are then ‘restoried’ by the researcher based on narrative elements such as the problem, characters, settings, actions, and resolution. ‘Restorying’ attempts to place the story chronologically in time. When a participant does not tell the story sequentially, the researcher often provides the missing causal links among ideas.

Bruner (1990) proposes that humans are naturally inclined to storytelling and that it links the exceptional and the ordinary. In this study, the ‘exceptional’ is the loss of the child, and the ‘ordinary’, is how the parent tries to subsequently construct her or his life. The final quality of the narrative for Bruner is the individual’s understanding of facts. What matters is how the person has constructed the events for a coherent story. This is consistent with the constructivist stance which postulates that we create the world that we experience and the realities to which we respond (Mahoney, 2002). The events themselves are not meaningful but instead, the individual tries to make sense or make a narrative of the unfolding events. Ellis and Bochner (2000) describe narrative inquiry as “stories...showing...characters embedded in the complexities of lived moments of struggle, resisting the intrusions of chaos...trying to preserve or restore the continuity and coherence of life’s unity in the face of unexpected blows of fate that call one’s meanings and values into question” (p. 744). The narrative approach is well suited to this study in that its focus is on the individual’s efforts at trying to understand or find meaning (Chase, 2003; Fraser, 2004) after the loss of their child.

From a methodological perspective, the interview schedule was originally designed chronologically, as the experiences unfolded over time. The parent was

invited to begin by describing his/her child, to talk about the child's illness and dying, and then to describe the parent's bereavement experience over time.

Riessman (1993) states that where one chooses to begin and end a narrative can shape its meaning. I chose to begin with a description of the child so that parents had an opportunity to talk about their child. I believed that this approach would not only set a trusting climate at the start of the interview, but also, during my collaborative inquiry with the bereaved mother, it was evident that she had fewer opportunities to talk about her child as time passed and she missed having those opportunities. I then chose to continue the interview with a discussion of the child's illness and the parents' experiences of the illness, hospitals, and treatments. By taking this approach, I was attempting to contextualize the parent's coping skills. I then continued sequentially in time to the present so that the 'story' would unfold. Questions were posed in an attempt to open up topics for conversation (Mishler, 1990) but were used to gently and loosely guide the narrative.

The research was developed to fill a void in the meaning-making literature. Previous research has described the meaning outcomes of bereaved people (Calhoun & Tedeschi, 1989-90; Saiki-Craighill, 2002) but very little has focused on the process of meaning-making in bereaved parents. Therefore, the interview questions were created to engage that inquiry by inviting parents to share their story. The original questions were developed from a literature review (Patton, 2002) and then sent to 3 independent reviewers (Lincoln & Guba, 1985). Two reviewers were bereavement counselors and one was a bereaved parent who was also professionally affiliated with a bereavement support group. Feedback was

given on the appropriateness and relevance, and wording of the questions.

Additionally, I had been part of a six-month collaborative inquiry with a bereaved mother for one year prior to the beginning of this project where themes I had noticed in the literature, such as social support, coping, emotional responses, and meaning were evident. These themes also helped shape the original topics and questions that guided the interviews.

Once the design of the study and the interview approach were determined, the research proposal was submitted for Ethics Review at Concordia University. No revisions were required of the original proposal, and ethics clearance was granted on April 11, 2003.

Interview Procedure

Creswell (2003) suggests that qualitative research should be conducted in a natural setting. To help build a trusting relationship (Fraser, 2004), the location and time of the interview was set by the parent. Most parents chose to be interviewed at their home. One participant was interviewed at the bereavement support centre, while another was interviewed at her place of work. By enabling the parent to set the interview location, I could also observe other aspects and details of the parent's world (Creswell). For example, some parents shared photographs of their child, which allowed me to put a face to the child and image to situations that the parents shared.

Each study participant was given a letter of introduction (Appendix D) that outlined the nature of the study, the purpose of the inquiry, his/her role in the project, to whom at the university they could contact if they had any ethical

concerns, the data management plans, and the meaning and purpose of “consent” (Lincoln & Guba, 1985). All participants were asked to sign a Consent to Participate form (Appendix E), and where parents were interviewed, a Consent to Interview form was signed (Appendix F).

Each interview began with some casual conversation to help develop rapport (Fontana & Frey, 1994; Patton, 2002) and to help make the parent feel comfortable. Additionally, I was highly aware that we would be discussing a most intimate and painful experience and so trust was paramount to the engagement. Since “the ultimate credibility of the outcomes depend[ed] upon the extent to which trust has been established” (Lincoln & Guba, 1985, p. 257), at the outset I took considerable time with this initial interaction if it became clear to me that the parents had no other time commitment. This initial interaction usually lasted approximately 30-45 minutes before I inquired if they were ready to begin the interview. The interview itself ranged from 90 – 150 minutes. Some parents also asked personal questions about my experience with parental bereavement and these were answered honestly. Patton considers this an aspect of triangulated inquiry whereby I could reflect on their personal questions posed to me.

Qualitative Data Recording Procedures

Raw data in qualitative data collection are the words that participants speak. To ensure accuracy, it is essential that these words be transcribed verbatim so that the voices and stories of the participants are represented authentically. One of the primary ways to ensure an accurate account is to tape-record the interviews

(Creswell, 1998; Lincoln & Guba, 1985), an approach that I used to analyze the data.

Notes were also taken during and after each interview. Patton (2002) emphasizes the critical role of note-taking to ensure the "rigor and validity" (p. 383) of the study. Patton states that note-taking helps the interviewer in a number of ways. First, it helps the researcher formulate new questions. In this study, parents raised different issues, some of which I then pursued at subsequent interviews when applicable. For example, some parents reported that they thought about or engaged in passive suicide attempts. Where parents indicated this, I inquired further. Second, note review done before the data collection was completed helped ensure that the inquiry was unfolding in the direction suggested by the study design, so that emergent themes could be pursued. It also helped to ensure saturation of the themes. Both descriptive and reflective notes were taken (Richardson, 1994). Descriptive notes acted as a back up to the audiotape. They were my summaries of what the parent said and any nonverbal gestures of the parent during the interview. Reflective notes focused on my impressions, ideas, and personal feelings. These were recorded both during the interview, as well as immediately after the interview was completed (Creswell, 1998; Patton, 2002). After the interview is complete, Patton makes recommendations for areas on which to reflect. These include asking questions about where the interview occurred, how the participant responded to the questions, and how well I thought I asked the questions. For example, the interview that took place at the parent's place of work, I was very aware that the comfort level may have been different than if we had done it at her home. It was also difficult to

say how much the location affected her focus on work-related themes. More so than other parents, she raised her professional self and work-related issues. These two forms of note-taking are distinct in that the descriptive notes focus on observations while the reflective notes push the data to another level that may include questions about method, theory, and my personal experiences. Reflexivity and bracketing will be discussed further below.

Interview Approach

Taylor and Bogdan (1998) suggest that interviews are one of the best methods for understanding the perceptions of participants or learning how informants come to attach certain meanings to phenomena or events. An interview guide (Patton, 2002) was developed to provide a framework for the interviews (Appendix G). The interview guide was developed using themes that were identified in both the literature review (Creswell, 2003; Patton) and the collaborative inquiry with a bereaved mother. The interview guide was prepared to ensure that basic lines of inquiry are pursued with each interviewee (Patton). Patton suggests that the advantages of the guide are that it ensures that the interviewer makes best use of the brief time available, and that the interview is systematic and comprehensive within the limitations of the research questions. Thus, open-ended questions and when required, probes were used to gather the data.

The grounding and orienting themes that guided the inquiry were social support, coping, emotional experience, and meaning. The questions were also developed to gather data on the research questions that had been identified. Consistent with narrative inquiry, the questions were written in a linear time frame

beginning with the child's illness. The order and wording of the questions was responsive to the parents and their context and style of speaking. These questions were developed originally as guides to assist me as the researcher, but it quickly became apparent that parents naturally discussed these areas. Nevertheless, the guide provided a reference point and a place to locate the stories that parents described. Additionally, what emerged from the interviews was that time was a difficult concept for some parents. Many events could be recalled in distinct time frames; however, the evolution of meaning was so gradual, parents had difficulty stating a specific time when they found meaning. Themes that seemed to be embedded in more external events or obvious changes in experience such as social support, ways of coping, and emotional experience could be put into the time frames much more easily by the parents. Furthermore, as Tulving (2002) states, the psychological reconstruction of time is not linear. As a result, parents often spontaneously moved through time as they discussed their experiences. When it was unclear what time period a parent was discussing, I asked for clarification (Patton).

Questions included a variety of question 'types' (Berg, 2004). These included, essential questions which were about the central focus of the study, throw-away questions used for climate setting purposes which addressed such things as demographics and hospital experiences, and finally, probing questions to help draw out a more complete story (Berg, 2004).

Patton (2002) states that an interview often begins with a standardized set of questions and then moves into a more informal conversational tone. He

recommends that the interviewee become actively involved in sharing descriptive information early. Therefore, the first question encouraged the participant to describe his/her child. This question was chosen to help ease the parent into the discussion and to give them an opportunity to talk about their child. As mentioned previously, this proved to be a helpful inclusion because most parents reported that they have fewer and fewer opportunities to talk about their child as the time passes. This question also proved to be helpful because it provided a context for an emergent theme of development of the relationship with child. While all questions in the interview guide were not asked of each participant, the four themes identified above- social support, coping, emotional experience, and meaning - were asked in each time frame and were asked in a conversational manner (Ollerenshaw & Creswell, 2002).

All interviews began with a description of the child and the illness experience and moved into feelings experienced in the first time frame of the first six months. This is in accordance with Patton's (2002) suggestion that opinions and feelings are usually more meaningful once the participant has relived the experience. This opens the participant to discussing feelings and opinions. However, how each participant discussed their bereavement was unique. Thus, the time frames were not strictly adhered to in a linear way but were nevertheless, covered during the course of the interview. If a parent moved ahead in time because they were reminded of a story or incident, then every effort was made to then return to the previous time period once that story had been completely discussed. This was done to ensure that each of the orienting concepts had been addressed at each time frame.

The wording of the interview questions changed with each participant. For example, a question was often asked at a particular time because the parent raised the topic independently. For example, an open-ended question was always asked of parents regarding their feelings, “Can you tell me how you felt in those first few months after your child died?” One parent talked in some detail about feeling alone and lonely, so I pursued this with her, “You said that you felt alone and lonely. And I’m wondering if you... if you see those as different” to which she described the different experiences she had of feeling alone and lonely. Additionally, new topics emerged from the interviews from time to time and these were often included in subsequent interviews. Therefore, the interviews were always flexible and responsive to the emergence of topics (Creswell, 2003; Patton, 2002). For example, re-constructing the participant’s feelings towards spirituality emerged as an important way for most parents to connect with their child. Some parents felt self-conscious about describing stories of their spiritual connection while others felt very comfortable. Therefore, I became attentive to the parent’s comfort level and openness.

Patton (2002) emphasizes ensuring clarity of the questions and to understand the language used by the participants. This can be obtained via previous research, inquiring about the language used among the group being explored, and by checking with the interviewee during the interview. This question of clarity was raised when I initially used the term “anniversary” to connote the date of the child’s death. I have always found this term inappropriate and so I was often reluctant to use it but did not know of another word. During one of the early interviews, one

mother said she preferred “angel day”. Subsequently, I would check in with each parent about their preferred wording.

Patton (2002) also suggests that illustrative examples in questions can help establish neutrality. Many parents reported that events or occurrences in the environment were felt to be a sign or message from the child. Some parents were initially reluctant to share their specific experiences. When I conveyed to them that I had heard many other parents describe these experiences, they felt much more comfortable sharing. While describing these experiences, they typically seemed to light up emotionally. For example, one mother recalled a trip in another country where she saw a child who had the same name as her daughter and who wore a shirt with a symbol the mother had come to attach to her daughter. She smiled and became more animated as she recalled the experience. The mother interpreted this to mean that her daughter was with her no matter where she went.

Because of the narrative quality of this study, the interview was originally designed to go from the past, to the present, and oftentimes, into the future. Patton (2002) states that this transition format lets the participant know that one section has been completed and a new section is about to start. Therefore, I always clarified when I was moving ahead in time. If a parent had moved back or ahead in time in a story, I followed up with probe questions, such as “when did this happen?” I also used elaboration probes (Patton) to ask the parent to provide more detail about their story. All interviews ended with a similarly worded question “is there anything else you’d like to share” or “have we missed anything?”

As can be seen, the interview guide was used in a very flexible manner out of respect for the loss and trauma being discussed. Questions were not asked if parents had already discussed a topic. If I wanted to confirm that they had nothing further to add, I checked in with them. Questions were rarely asked as they were originally written. Rather, the participant was able to steer the pace and direction of their narrative in a conversational manner that suited their comfort level and openness and was reflective of their experience. Topics that the parent spontaneously raised were receptively heard and at times pursued further with other parents if the topic emerged.

Despite the benefits of engaging parents in an interview, Creswell (2003) notes that some of the limitations to interviews are that the information is indirect, the researcher's response may bias the responses, and people are not equally articulate or perceptive. These limitations are acknowledged within this study and will be discussed in the section pertaining to my reflexive practice.

Data Analysis

All interview data were audio-taped and transcribed using verbatim transcriptions. All written responses were converted into a computer file. N-VIVO, a data management software program, was used to assist in the management of the data analysis. N-VIVO allows the researcher to code interviews in the same way one might code transcripts with pencil, markers, and paper or cards. Once a transcribed interview has been entered into the program, the researcher can read the transcript and write codes along the margin beside the text, with the relevant text highlighted to that code. As well, memos can be added to text for later reflection. Advantages to a computer data management program are that the reports or

summaries of all the quotes related to a particular code or group of codes can be easily generated. Additionally, the frequency of codes can be obtained to see the prevalence of a code (Creswell, 2003).

The five major themes that emerged from the analysis were parents' emotional experiences, their change in their experience of social support over time, the change in their coping efforts over time, the change in the parent-child relationship, and the process of meaning-making. These categories emerged from an analysis of the sensitizing concepts which Blumer (1969) defines as "a general sense of reference" (p.148) and suggest avenues of investigation. Many of these concepts were "emic" meaning that they emerged from the participant and not from the theoretical or research literature (Bruyn, 1966) while others were "etic", or emerging from the researcher's perspective. A process of coding, identifying themes, and clustering the themes guided the analysis (Creswell, 1998; Marshall & Rossman, 1999; Miles & Huberman, 1994).

Coding interwove two approaches. First, the data were coded by following the more commonly used approach of open, axial, and selective coding (Strauss & Corbin, 1998). However, due to the narrative quality of this study, a more narrative-based approach first proposed by Clandinin and Connelly (2000) and developed further by Ollerenshaw & Creswell (2002) also guided and informed the analysis. This Three-Dimensional Space Narrative Structure includes three aspects: interaction, continuity, and situation. Interaction involves the personal and social. Personal aspects to be considered include looking inward to feelings and hopes such as the feelings of grief and the hopes for relief. Social aspects include looking

outward to existential conditions in the world with others and their assumptions and intentions. For example, this may relate to others' opinions about death and how this affects the parents' struggles. Continuity considers the element of time. Therefore, past reflections consider memories of experiences, feelings, and stories from earlier times. Parents may recall happy and painful times while the child was alive or vividly recall the moment the child died. The present time frame considers the current experiences, feelings, and stories that are related to the pivotal event. Parents can relate the current feelings of contentment in relation to past feelings of grief. The future looks forward in time with imagined experiences and plot lines such as envisioning the future journey of their meaning-making. The third aspect is situation or place. Here the researcher considers the storyteller's descriptions of places. Parents can recall hospitalizations while the child was ill and significant places such as the child's bedroom and cemetery plot after the child died.

Both analytic approaches require a reading and re-reading, and in my case, re-listening to the audiotapes. Re-listening to the tapes was advantageous so that I could re-imagine the interview more clearly and also to hear the tone and affect in the parents' voices. Therefore, the three themes of interaction, continuity, and situation helped guide and inform the axial and selective phases of coding, all the while, being open to the emergent themes. For example, interaction or social support as it was named in this study, was pursued across time (continuity), and place (situation) to see if it changed. However, spirituality, which fell under the theme of meaning, cannot be easily fit into any of the categories of interaction, continuity, or situation.

Open coding of the data (Strauss & Corbin, 1998) resulted in 169 codes. These codes were words that either duplicated or mirrored the spoken word of the parent known as *in vivo* codes (Creswell, 2003). For example, one parent described one of her early feelings as “hole”. The word “hole” then became the open code. Despite being sensitive to the interaction, continuity, and situation, I remained open to emergent themes that may not have fit under these headings. For example, as mentioned above, spirituality emerged as a category under meaning. While this may fit into the interaction aspect, one might propose that it extends beyond. Open coding requires that critical terms, significant events, or themes are recorded. The researcher can use a theoretical frame provided she remains flexible to what emerges (Neuman, 1997). Open coding comes from the researcher’s initial question, concepts in the literature, from people in the setting, or new thoughts inspired by the data (Neuman; Patton, 2002). N-VIVO allows for an easy display of all the open codes so that re-working of the codes could be managed easily. Saturation of each of these codes was obtained wherein no new categories emerged.

Axial coding requires the researcher to review and examine the open codes with a view to assembling the data in new ways after open coding (Neuman, 1997). Neuman states that “codes should relate to one another in coherent, study-important ways” (p. 423). Axial coding allows the researcher to investigate central phenomenon, actions and interactions that result from the central phenomenon, and outcomes of the central phenomenon (Creswell, 1998). In this phase, axial coding was also considered via the three-dimensional approach described above. Therefore, I sought to examine whether situation, continuity, and interaction could

guide the open codes. This is consistent with Neuman's recommendation that during axial coding, the researcher asks about causes and consequences, conditions and interactions, and processes. Axial coding was done through N-VIVO but also by "wallpapering the dining room". I felt visually constrained by N-VIVO in trying to see how all the codes could be thematically arranged. Therefore, I took flip chart paper and taped it to the wall with the codes written and then variously arranged until the five primary themes emerged. This 'wallpaper' also helped during the selective coding phase.

Axial coding resulted in the creation of five primary themes. The first theme related to social support. *Social support* encompassed any references to the parent's experiences with family, friends, professional, and support group. Therefore, it covered personal supports and personal relationships as well as those people who were sought specifically for their knowledge or experience in bereavement. It also included positive and negative experiences of social support. The second theme was *emotional response*. Emotional response encompassed negative emotions such as crying and anger and positive emotions such as peace and happiness. The third theme was *coping responses*. Coping encompassed responses related to emotions such as consciously choosing to watch videos of their child for the main purpose of trying to cry, maladaptive coping responses such as passive suicide attempts, and adaptive or mobilizing coping responses such as seeking help or journalling. *Relationship with the deceased child* was the fourth theme. This theme encompassed the parents' description of the changing relationship to their child. This theme addressed the parents' description of their child prior to the death and

how the relationship came to be redefined after death. Parents' descriptions of their relationship to the child prior to death provided temporal information for understanding the evolution of this relationship after the child died. This theme also described how the parents' relationship with their child helped them reconcile their spiritual beliefs. And finally, the fifth theme, and central phenomenon, was *meaning*. Meaning encompassed descriptions of spirituality, lessons learned, changes in behaviour, acknowledgement of journey or process, and outcomes of growth or benefit.

As can be seen, axial coding incorporated the three aspects of the Three-Dimensional Space approach but also included other codes. Interaction codes related to the theme of emotional responses that parents experienced over time, and also to the social support and the ways parents chose and continue to choose personal relationships. With respect to the temporality aspect, each of the themes changed over time but the changes were not necessarily linear. There was fluctuation within each of the themes showing efforts at adaptive and less adaptive responses. And finally, situation considered the various physical settings that parents described over time such as the hospital, and the significance of the child's bedroom for connecting to the child. However, the theme of coping responses does not neatly fit into any of the three headings, but may possibly fall under the interaction heading. Coping responses can be viewed temporally but it reflects the parent's active involvement in the bereavement process. Therefore, the Three-Dimensional Space Narrative Structure does not provide the structure to clearly and fully describe the parents' coping responses. Additionally, the interview focused

more on the past and as such, was more retrospective in nature with less attention paid to the future.

The final phase of coding was the selective coding process which requires the researcher to develop a storyline that integrates the codes derived from the axial coding. Both coding approaches (Open/axial/selective & the 3-Dimensional Space) concur that a storyline or narrative is the outcome of the coding. Because the interview format identified time frames, the five primary themes were reviewed in light of these time frames. Confirmatory and disconfirmatory quotes and cases (Patton, 2002) were also reviewed in an iterative way. For this study, selective coding resulted in a description of the meaning-making process that was informed by the five themes derived from the axial coding, and will be discussed later in this thesis. This process describes their unique contributions as well as areas of overlap among them over time.

Verification Procedures

Lincoln and Guba (1985) established standards by which we can determine if the data gathered are valid and reliable. Credibility is the qualitative equivalent to internal validity, transferability is the equivalent to external validity, dependability equates to reliability and confirmability is equivalent to objectivity. These methods of meeting trustworthiness will be discussed in relation to the current study.

Credibility can be achieved through a variety of techniques including triangulation, peer debriefing, negative case analysis, and member checking (Lincoln & Guba, 1985). The original intent of this study included a triangulation

of methods (quantitative and qualitative data collection methods) but as previously mentioned, the sample was insufficient for quantitative analysis (although, some significant findings suggest areas for future inquiry). Patton (2002) also suggests that reflexive questions can be considered as a triangulated inquiry. From this perspective, the researcher is asked to consider the cultural, social and ideological origins of one's own perspective as well as those who are interviewed and those who read and evaluate the report. The three parts of this inquiry are reflexive questions about the participants (How do they know what they know? What has shaped their worldview? How do they perceive me? How do I perceive them?), about the audience (How do they make sense of what I give them? What perspectives do they bring to the findings?), and about myself (What do I know? What has shaped my perspective? What do I do with what I have found?). During my reflexivity I spent time on each of these areas. This will be discussed more below.

Peer debriefing, whereby the researcher confers with relevant sources of knowledge/experience, was done during the design phase of my study with bereavement counselors and a bereaved mother, and again throughout my study with my supervisors. As mentioned previously, the initial research questions were informed by my collaborative inquiry with a bereaved mother and through the literature review. These sensitizing concepts were then brought together for review by two bereavement counselors and a bereaved parent who worked at a bereavement support group. These three people provided feedback on the appropriateness, relevance, and wording of the questions. During the interview

stage, I spoke with my academic supervisors. In this phase, I discussed my questions and concerns regarding my method, my biases that may hamper my interpretation and interaction, and any ethical concerns regarding information divulged. In particular, I was keenly aware that my professional experience was the source of my primary knowledge regarding childhood illness and death. Undoubtedly, this provided some privileged experience but nevertheless, I had to remain an observer to the participant and the research process. Therefore, the understanding derived from my past work provided a context to discuss its effect/impact on my current experience.

Negative case analysis is another way to ensure credibility. Lincoln and Guba (1985) do not suggest that all cases must fit the conclusions drawn. During the course of my analyses, I reviewed the process, the quotes, and the descriptive aspects such as gender, or location of interview to understand where parents may report different experiences or feelings.

Member checks are another way of ensuring credibility, which I incorporated into my study. I selected a representative sample of six parents. These parents were chosen for their representation across the 'time since death' categories. Therefore, three parents whose child died less than five years before, two parents whose child died between five and ten years ago, and one parent whose child died more than ten years ago provided feedback. These participants provided written feedback to the draft description of the meaning-making process. Where this sub-sample of parents agreed, modifications to the process of meaning-making were made. In fact, very little change was required.

Transferability, the equivalent to external validity (Lincoln & Guba, 1985) is found through thick description and purposeful sampling. Thick description is achieved through the data and quotes and is intended to both help the reader understand the phenomenon under study, and to be able to draw their own interpretations about meanings and significance (Patton, 2002). Throughout the results and discussion sections of this thesis, quotes are used to provide the reader with a closer experience of bereaved parents. The second way of addressing transferability is through purposeful sampling. In this study purposeful sampling was performed by including only parents bereaved by illness and whose child died between six months and twenty years ago.

Dependability of the data collection methods and analysis is the equivalent to reliability (Lincoln & Guba, 1985) and can be achieved by an audit of the process and the product. An audit can be done on the raw data, the field notes, the data reconstruction, personal notes and instrument development. Each of my supervisors played an important and critical role in this process. A review of the codes was done to ensure that I stayed close to the participant's words. As well, each provided feedback on the development of the interview, and on the various aspects related to the interview and subsequent analysis.

Finally, confirmability, equivalent to objectivity, (Lincoln & Guba, 1985) coincides with the audit described above and also with the maintenance of a reflexive journal. Reflexivity will be discussed in greater detail below.

Researcher Role: Ethical Issues and Reflexive Practice

Reflexivity is a concept in qualitative research that explores how well one can put aside personal feelings and preconceptions (Ahern, 1999), and as well that one has the capacity to reflect back on oneself and use oneself as an object of reference. Therefore, in a reflexive process, one looks honestly at one's behaviours, feelings, and motives. The process of bracketing is a reflexive, iterative one whereby the researcher spends time trying to understand her experiences (Ahern; Lincoln & Guba, 1985) and how they may have impacted the research process and interpretation of the data. Narrative research is a highly personal method of inquiry. The stories of the participants are detailed and in this case, emotional. Thus, to ensure that I understood what the parents were saying, I needed to reflect on any biases, subjectivity and my ethical integrity, and bracket (Creswell, 1998) or make those distinct from the parents'. Because of my previous experience as a therapist and as a professional in pediatric oncology, it was important that I check on my role during the interview, and that I did not respond as a therapist, but as a researcher. As Josselson, Lieblich, & McAdams note (2003), "all successful interview-based research is grounded in good listening (p. 8) and my therapeutic background prepared me for this task. In fact, Ellis and Bochner (2000) somewhat jokingly say, "therapeutic training probably should be a prerequisite to being an ethnographer" (p. 754). Based on my experience in pediatric oncology, I noted the variety of coping mechanisms and the resultant effects on parents' emotional, psychological, and physical well-being. However, while working in pediatric oncology, parents also held on to hope that their child would survive. I was now meeting parents

whose hope and dreams had been shattered. Therefore, I tried to remain open to their unique voices.

My previous experience in pediatric oncology as an art therapist also gave me skills in asking follow-up questions, or trying to see if concepts raised by the participant were related in any way. Through my past therapeutic experience, every effort was made to ask questions in a non-directive but interview-focused way. It was important that I acknowledged times when I wanted to pursue a line of questioning that was unrelated to my research topic. Instead, I wrote these questions down afterwards in my reflexive journal with the thought that some of these questions might provide areas for future inquiry, and for further and deeper probing into the transcripts.

I also reflected on my lived experience. I have never parented a child and I often questioned how this may affect the depth of my understanding. Some parents inquired about my parental status. At times I felt woefully inadequate and worried that because I did not share the parents' experience, they may have some resistance to me based on some of their past negative experiences with others. And while I cannot know what a bereaved parent may feel, parents indicated that the questions and my responses were thoughtful, respectful, and empathic.

During the interviews I checked my probe questions several times for appropriateness before asking the parent. Glaser and Strauss (1967) recognize the value of the subjectivity of the researcher stating, "the root sources of all significant theorizing is the sensitive insights of the observer himself" (p. 251). The interview

relationship with all participants was informal and friendly. For example, when the interview was held at the home, parents made tea or coffee for the interview. Patton (2002) emphasizes that the interviewer “must have the utmost respect for these persons who are willing to share with you some of their time to help you understand their world” (p. 417). I remained very aware that for most participants, I was a stranger and they were willing and open about talking about an incredibly sensitive and painful experience. Thus, I followed their lead on how much depth to probe further into various issues that arose in the interview.

Issues that emerged in previous interviews were often incorporated into subsequent interviews. For example, I had mistakenly assumed that recalling events in a linear way would not be problematic. For some issues, this proved not to be true. Consequently, I incorporated how difficult it could be recalling events in a sequenced way. Other reflexive opportunities came during discussions with my academic supervisors. Two supervisors provided regular feedback on my questions, ‘meanderings’, and feelings elicited during the interviews. Also, in accordance with a qualitative approach, the research literature was consulted as part of the iterative process. As mentioned above, the literature provided topic headings to pursue, but how these themes would unfold was unknown. Finally, I was aware that some parents were more articulate than others and I had to ensure that I did not always go to those parents for quotes.

With respect to the data, access to the raw data was limited to my two academic co-advisors and me. All interviews were transcribed by a transcriber who was trained regarding the importance of confidentiality. Ethical procedures

regarding handling of the tapes was conveyed and was respected. While the transcriber knew the first name of the parent interviewed, no other information was given other than what emerged in the interview. Additionally, only two participants came from the transcriber's community. Handling of the raw material was also handled in accordance with ethical guidelines. The tapes of the interviews and all consent forms that were completed by the informants were stored in a locked filing cabinet as per the ethics protocol approved by the university.

FINDINGS

The Process of Meaning-making in Bereaved Parents

The face-to-face interviews of 11 parents, two written responses to the interviews, and the written responses to the six-item version from all 16 parents provided the data for the qualitative analysis of the following research questions:

How do parents describe their bereavement experience since their loss?

My sub-questions are:

- 1. Do parents describe finding meaning/benefit/growth/purpose after the loss of their child, and if so, how?*
- 2. What are the meaning outcomes defined by the parents?*
- 3. During the course of bereavement what is the role of social support?*

Following the narrative method the following section summarizes parents' descriptions of finding meaning from the loss of their child divided into time frames. The time frames were chosen based on previous research reviewed in the literature. As mentioned previously, existing research has described and

documented the first two years of bereavement but little research has been done on the time after two years. Literature suggests that a number of factors potentially affect a parents' search for meaning, but how these factors affect the process is not clear. This study attempts to describe the meaning-making process in greater detail. The participant names are pseudonyms and the dates recorded are by month/year only to protect confidentiality.

The following summary uses the five themes as headings for the presentation of the process of meaning-making: emotional experience, coping efforts, social support, relationship with child, and meaning efforts and outcomes. Then a presentation of how the themes inter-relate will be described.

The First 6 Months

Emotional Experience

Parents reported that the intensity and unrelenting nature of the pain during this time was unavoidable. In this early period after the loss, parents described the pain with words such as “black”, “depleted”, “despair”, “hole”, “inconsolable”, “empty”, “half-dead”, “alone”, “longing”, “no more joy”, “paralyzed”, and “rock bottom”. Some stated that they didn’t realize how physical the pain in grief could be. The most commonly described emotional experiences seem paradoxical. At one end parents described feeling numb, empty, lost, unable to feel, and that there was an unreality to the experience. At the other end, parents reported feeling depressed, angry, guilty, suicidal, judged by others, and experiencing unrelenting pain. Thus,

at one end there was numbness or an inability to feel and at the other end there was an intensity to the pain that was overwhelming.

Parents reported expressing these emotions in a variety of ways. Most parents cried often and sometimes, uncontrollably. Sophia conveyed the intensity of her crying in this way,

Um, and I remember referring to crying as my way of sex. Like feeling after a good cry like I was feeling after a good orgasm. It was that type of release.

Like I would cry, and it would be so deep, it would be so, so, so deep that, you know when you're not sure if a person is crying or laughing? Out of control, totally. Like, you get to the same place it seems. And that's where I would go. And boy would I cry! Cried, cried, cried, and when I did that, I felt so good after! It was a real release. (July 2003)

Parents would engage the pain by sitting in the child's bedroom, holding or carrying some item of the child's such as a blanket, piece of jewellery, or clothing. These items held either symbolic meaning for the parent or contained a sensory link to the child, usually olfactory. And this engagement would provide both comfort and conversely discomfort or grief.

A common challenge shared by parents was how to spend the day. Many parents cared for their child for many years and consequently this care became a routine part of the parent's day. Administration of medications and treatments, visits and stays at the hospital, and decisions about vacations were constant considerations for the parents. Parents viewed this role as their job or vocation and one that they did with great care and conviction. Annette juxtaposed the feelings

after her daughter died with her experiences while her daughter was alive, “and it was like ‘what now’? I didn’t know what to do. I didn’t know what to do with myself. It was like there was a purpose for living, Pam [daughter] at the time. But with her illness...I was so consumed in all that because it took over everything.” (February, 2004)

After the death, parents found that their day lacked purpose and routine. Thus, their primary role in life had ceased, creating a very unfamiliar and purposeless existence. Patricia captured a number of these feelings when she says:

And afterwards, I think I hadn’t been in my house for so long because I had been [in the hospital], that it was like coming into a strange land. The house was empty, and um, I think I was numb. I don’t think I liked spending time in the house - I wasn’t used to it. Suddenly I was here all alone and um, it was empty. I was probably numb for a year. I mean, I don’t even know. I can’t remember. I would like to try to think – when did I stop crying myself to sleep? When did I start listening to people? I don’t know. (December, 2003)

This lack of purpose combined with the intense feelings often contributed to parents feeling like they were on “automatic pilot”. Parents would say that they moved about the world like a robot, not being able to focus or concentrate on the task at hand, wondering how they arrived at a destination, forgetting why they may be at a store, not focusing on a conversation, and not being able to get up or get dressed. Many parents also felt that their other children received less attention because of the intensity of the grief during this time. In those situations parents expressed deep regret for their inability to care for their other children in a way they

would have preferred normally. For those parents who lost their only child, the house seemed too quiet and the ticking of the clock seemed to tick like a bomb as it marked the passage of time. One mother who lost her only child said, “Um, well, (pause) I felt like my world was very silent. And it was so silent that it was hurting my ears. Like, the complete oxymoron of it. Silence was deafening? And that was very painful. Very, very, very – very painful.” (Karen, February, 2004).

Commonly held beliefs or assumptions about the world such as the world being fair, benevolent, just, and that humans have a great deal of control over their destiny were commonly shattered. Some felt angry at God for betraying them and that it was unfair that their child died before them; however, this questioning and trying to make sense seemed to occur more during the illness than after the death. (This will be discussed more under the Meaning theme.)

The most salient shattered assumption was the loss of control. Parents felt that if their child died, then nothing was guaranteed and if something could go wrong, it would. Thus, parents didn’t feel that they could count on day turning into night, spring becoming summer etc. Consequently, parents felt very protective and worried more about their other children and their spouse. This lack of control made parents feel highly vulnerable. This mother who lost her teenage daughter realized, “We have no control over anything. That was the hardest thing I had to learn.” (Joan, October, 2003).

Despite feeling betrayed by God, parents largely retained a belief in a higher power but felt confused about their beliefs. Maintaining a belief in a higher power meant that when they died, they would see their child again and this provided a

great deal of comfort. However, this belief also provided some conflict. While parents desperately wanted and needed to see their child again, they realized that this could only happen if they too died. And for many, dying was a considered option. Ambivalence about living led to reckless driving or risky behaviours. Suicidal feelings were represented in these passive attempts rather than active behaviours. This mother explained her reason for living after losing her only child,

And to this day as a bereaved parent, um, I'm so glad I believe in heaven.

Because if I didn't – I'd be a very sad and a very depressed individual. In fact I probably – I've talked about this with friends – I can see why people commit suicide. Um, if you don't believe there's a better place, then why go on?

Cause really, my life ended in a way when Kara died.” (Karen, February, 2004).

Parents had to ask themselves if there were any reasons to keep living and for most, it was to care for their other children.

Therefore, the emotional experiences described by parents were sometimes paradoxical. Parents felt great pain but also felt numb. Parents felt that their fundamental assumptions and beliefs had largely been shattered; however, almost all still retained some level of belief in a higher power. Parents felt they had little control over their emotions and that outbursts of emotion were unavoidable. In fact, parents made efforts to engage the pain, as will be discussed below.

Coping Efforts

Parents dealt with their emotions in an oscillating fashion. At times parents made conscious efforts to feel the pain by going to the child's room or cemetery, or

looking at pictures. And at other times, parents would need to pull back from the pain by focusing on other things. Frank described his varying response to the painful ‘stimuli’ of driving by the hospital,

I don’t, like as far as going, going by the children’s hospital, um, because it, well let’s face it; I mean that’s, (choked words) I guess whether Candace was sick or not, it makes me remember. ...it makes me remember her death, but it makes me remember, because I mean, that was (clears throat) those times that she was in hospital there were intense times, ...because I mean we spent so much time there, you know. And I don’t, I, do I, I don’t really want to forget that, (softly) I do and I don’t I guess. But uh, those things help me, I guess, those things force me to, to remember. (October, 2003).

Patricia described how she would engage her grief through smell, “Um, he had his one little fleece thing that he wore all the time that I would just go and I would smell it. It was the smell that I ... I used to do that.” (February, 2004).

Often parents also stated that they made efforts at being very busy, returning to work to be distracted, volunteering for many causes, or going on trips. These mothers describe their need to be busy or focused, “There was just a huge emptiness. And to fill that emptiness, which I think is still there, um, I took off at a dead run doing anything and anything to keep me busy. I overworked, I over volunteered, I over everything.” (Joan, October, 2003). “Throughout the months immediately after Tristan’s death I was running....I went to Europe for a month, um, and I started to take classes again, courses again.” (Sophia, July, 2003). These activities provided some respite from the pain for these participants. However,

particularly in this early phase, parents said that it was almost unavoidable, that to avoid the pain was very difficult. Parents would often avoid parks or school grounds, for seeing children the same age as their child. The pain and unfairness felt was profound. The challenge for these fluctuating feelings was that any avoidance of the pain often resulted in feelings of guilt. Parents reported that if they weren't thinking about their child or feeling their pain they felt that they had betrayed their child or that they were being a 'bad' parent.

Dealing with daily routines often seemed insurmountable. Such things as getting dressed seemed like a huge effort and so tasks were considered in small chunks only. Parents may have been able to attend to the task at that moment; however, it was difficult to plan or to see anything in a wider context. Living day-to-day was the best the parents could manage. Consequently, parents relied on the support of others to maintain the household. Ken described his coping and his needs when he says, "The changes continued though the pace was slow. I just went on day by day. My actions were motivated by my need to look after the other children. I needed looking after too but there was no one to do that" (August, 2003).

Only a few parents reported trying to journal their experiences at this time. Therefore, coping efforts largely revolved around engaging the pain such as spending time in the child's bedroom or avoiding the intensity of the pain by working or volunteering for many things. Other coping efforts included counting on friends and family to help with the other children and daily chores so that parents could either engage or avoid their grief. This will be discussed in more detail below.

Social Support

Social support provided by others in the first six months attempts to address the emotional and practical needs of the bereaved parent. Family and friends tried to “just be there” for parents emotionally, by sitting with the parent, going to the cemetery, or providing a shoulder to cry on. Others supported the parents instrumentally by helping with meals, chores, and the other children. Parents admitted that the presence of others left them feeling ambivalent, as stated by Annette,

Um, probably family and friends, just being there, just being in the house.

Um, as much as I didn't want to go around them, I didn't want to be without them. I just, nothing seemed to be satisfying. Nothing seemed to kind of meet any need that I had. And I think it helped that they were there, just because of my other, of my son, so that someone could take care of him.(February, 2004).

However, many parents admitted that despite the efforts, they were inconsolable. No matter what a person said or did, it couldn't take the pain away. Parents felt gratitude for the support but the pain was too profound to be relieved by others. These mothers reflected on their feelings about support at this time,

It really is, you know, there's nothing that takes that pain away. People can do all the most wonderful things in the world for you and say all the right words and it really doesn't matter. Those first 6 months it really doesn't matter (speaks slowly) what they do. There's nothing that's gonna come close to being helpful. You may understand in retrospect that there's been some help there. But you don't at the time. (Nora, October, 2003).

“People who were really nice to me after, you know, you never forget. I’m sure people say that. You never forget the people who... it’s a very difficult thing to console a bereaved, a bereaved mother.” (Julia, December, 2003).

Instrumental support was provided by friends, family, and the religious community. This support came in the form of meals, care for the other children, and daily chores such as laundry and cooking. Emotional support was provided by many but not by all. Many perceived that immediate family did not support them emotionally. In particular, most of the bereaved parents said that their own parents did not support them emotionally. When the bereaved parents were asked why they felt their own parents could not support them, they were stumped for an answer, possibly because they too were grieving. Parents continued to feel unsupported by their immediate family, which left them feeling angry, resentful, and misunderstood. Some of the bereaved parents did feel that they received some emotional support by family members but it was often an in-law who was most able to provide the emotional support. Some friends also provided emotional support but most parents acknowledged that people did not know what to say. Consequently, others would say nothing or would say something that was inconsiderate or judgmental such as “you can have another child”, or “at least you have other children”. Despite parents mentioning the deceased child in conversation or saying the child’s name, many friends and family would not follow up with the discussion. Parents felt that if they tried to talk about their child, it was a guaranteed way to create silence. This silence was experienced as hurtful by the

parent because they wanted others to remember their child and share stories as Nora recounted,

You know, um, giving somebody permission to say the name of your child is absolutely incredible. Because I remember thinking you know, I would have moments when I'd be with friends or family and I really needed to talk about Grace. But I would never be quite sure what the reaction was going to be.

You know, cause I didn't want to bring up her name and then have the topic change immediately, which is what would very often happen. But yet my best friend used to come over and sit on the couch and say "Do you remember that day with Grace when...". So what she immediately did was open a door for me. She gave me my 'in'. Okay, you brought up her name first, I'm taking that ball and I'm running. And she would sit on the couch with me for hours and just let me ramble and say the same things over and over again and you know, I've just told her since that I just admire your patience, it was just incredible! (October, 2003)

Some friends would try to help by providing distraction such as inviting the parent to social activities or events; however, parents did not have the emotional stamina to join parties. Parents also felt that they were judged for how they were grieving- too much, not over it, or too little because they were at the party. As well, parents often felt that they were labeled if they attended a social gathering- "that's the one whose child died".

Most parents felt that their spouses were a great support but that each spouse grieved differently. Initially this differing grief response provoked some conflict or

prevented the parents from discussing their differences; however, once the parents identified that this was the way she/he needed to grieve, the parents were able to let the other respond the way they needed. Very few were unable to reconcile their differences. As stated earlier, ten of the parents were still married to the parent of the deceased child. Most reported that their relationship strengthened during this time. For the three parents whose marriage ended, each parent reported that their marriage was troubled prior to the death and they attribute that the death catalyzed what was already inevitable.

Other support was found through the religious community and from acquaintances. The religious communities supported the parents through rituals such as Shiva and symbolic gestures at Christmas and Easter. Many felt that their minister or rabbi was of profound support. These parents usually had an ongoing relationship with the religious institution prior to the death. As well, these parents felt that the religious institution was supportive because it was a community, not just because of its focus on faith. For those whose relationship with the religious community was less personal, this support was not felt as positively. Some people that parents identified as acquaintances or with whom their previous relationship was professional such as a VON, became closer after the death. Parents felt that these people allowed them to talk freely and/or were able to name or identify the parent's experience with great understanding and compassion.

Generally, parents felt ambivalence about the social support they received. In this early period parents felt a need to isolate themselves and retreat from the world, yet parents also felt alone and lonely. Parents generally felt misunderstood but

because they did not have the energy for socializing, it was difficult to have opportunities to describe to others how they were feeling. Therefore, it was difficult to respond to the social support efforts that were provided and thus, the feelings of isolation and being misunderstood became self perpetuated.

Parents consistently reported that support gestures that were felt positively were from those people that allowed the parent to talk freely without judgement, that allowed the parent to be just as they were whether it be crying, laughing, or in silence. Additionally, parents deeply appreciated when others would talk about the child and provide any reminiscences, and for others to validate or name the parent's experience.

Well, I think validation is what's helpful. You know, not to try to say I know how you feel, that things will get better – that's not what bereaved people need to hear. What they need to hear is something um, more along the lines of 'I can see how terribly difficult and painful this is for you. I want you to know that my heart is going out to you'. Um, you know, not 'hang in there', but to recognize the profoundness of the loss and the depth of the pain.

Recognition and validation and you know, just, you know, you don't have to say anything... just listen! (Nora, October, 2003)

Parents appreciated unsolicited calls or dropping by to "just say hi", cards that told the parent they're being thought of, and acknowledgement of anniversary dates. Social support that was viewed as unsupportive include comments about "getting over it", about having other children, about God's plan, and refusing to talk about

the child. One mother provided some suggestions and then went on to describe an interaction her husband experienced,

Well you don't tell people that time will heal. (chuckles) You don't tell people like someone told me, your child's in a much better place. (chuckling) It's the typical things, I mean, someone said to my husband 'I wouldn't wish this on my worst friend'. (laughing quietly) Like he was an idiot, you know? I just - you just have to take it. And people don't know what to say. (Julia, December, 2003).

Social support in the first six months is the most intensive support that parents will feel. Despite the availability of emotional and instrumental supports, parents felt somewhat ambivalent about it. On the one hand parents deeply appreciated the efforts made by others because they acknowledged how difficult it must be, yet on the other hand, parents did not want to be around others. This paradoxical experience perpetuated feelings of loneliness and abandonment.

Parents provided practical suggestions to others who are in a position to support a bereaved parent. These suggestions included letting the parent grieve in their own way; do not judge the parent's emotions and behaviours; acknowledge anniversaries overtly or symbolically; and probably the one reported most frequently, let the parent talk about the child and offer some of your own stories and memories.

Relationship with Child

As a result of the serious and eventually, terminal diagnosis, parents' relationship with their child changed. During the illness, parents became "super

parent”, doing everything they could to protect their child. Annette reflects on being “super parent”,

If I don’t do this, she’s just going to get sick and she’s going to die. I mean, sooner than she would. So there I didn’t see it as an option, I mean, I basically you know, okay I’ve got to do this and I’m going to do it. Nobody’s going to stop, there was nothing that was ever going to come in between me and this child. (February, 2004)

And on the other hand, parents gained a tremendous respect for their child and often viewed their child as a teacher. Karen talked about what her daughter Kara taught her,

I just learned to believe that someone else was hearing me, even though they weren’t there. See, I guess in a way, because Kara was blind, I often referred – I think Kara’s blindness was one of the greatest gifts she had because it taught me to believe in something you can’t see. And Kara’s whole life was believing in things she couldn’t see. So she had to have faith. She had to have trust. (February, 2004)

These experiences continued to shape how the parents negotiated their relationship with their child after death. Parents were highly receptive to the environment. Parents wanted a message from their child to tell them that their child was alright, but also, to maintain a connection to their child. Parents occasionally had dreams that helped, but more often, parents would read the environment differently. Parents felt that these environmental occurrences were messages from the child and these signs provided great comfort to the parent. Carrie described this

awareness, “I guess you’re in so much pain and your brain is different or what, but you’re really acute – everything is just so, you’re aware of everything. You’re aware of the tree rustle, you’re aware of the sunshine, you’re – everything means something.” (November, 2003).

Parents also reported talking to their child out loud or in their head. Ron talked about the effect this had on his own brother, “probably about three days after Albert died and my family was here. I, I was like talking out loud to him and one of my brothers found that strange.” (December, 2003).

Therefore, parents were receptive to the environment so as to keep their child present in their lives. They also sought out ways to keep the child present such as talking to the child, and through the senses. Additionally, parents needed to know that their child was alright, thus parents still maintained their role as parent.

Meaning Efforts and Outcomes

Parents’ assumptions about the world were first shattered at the diagnosis. It was during this time, prior to the death, that these parents reported trying to make sense of the experience and asking the existential question “why?”. Annette described her wrestling with these questions during her daughter’s illness that lasted many years,

Um, how do you cope? Um, I don’t know. Religion in a way, I got very resentful, very angry. Why me, why her? You know, I mean not that I wanted that for somebody else, but you know, how can you do this? So, I used to go, we used to go to church on a regular basis and then sometimes I

just got, when things were bad I'd just, you know, kind of pull back and then we'd go again. (February, 2004)

After the death, meaning efforts in the first six months centred on a more spiritual nature. As described above, parents were highly receptive to the environment or to any other cues that would maintain the parent-child relationship. A few parents reported trying to be more active in making-meaning but in hindsight, parents felt that their efforts were premature. For example, one mother tried to put a kit together in the first six months after her child died. This kit contained a journal and pen and Forget-Me-Not seeds and was available to subsequent parents whose child died.

The emotional response to the loss precluded any significant active meaning efforts towards growth or benefit. Some parents reported that they wanted something positive to come of their loss; however, efforts to this end could not emerge for some time. In the member checking phase, Nora said that if someone had suggested that something positive could come of the death of her child, she would have been charged with assault. Some parents reported a heightened sensitivity to the plights of others and responded to those others' needs in the form of instrumental support. However, all parents admitted that the first six months is too early to make any efforts towards finding meaning or benefit.

Summary of the First 6 Months

The first six months after the death of a child is a profoundly painful period. The emotions are deep, they are felt in the body as a wrenching and ripping, and yet also, parents felt they were devoid of emotion. Coping efforts are centred on

negotiating these emotions by either avoiding them or engaging them. The support of others both helped and hindered parents. Parents felt that most support was intended to be helpful but every parent reported at least one incident that was felt to be insensitive, judgemental, or hurtful. At this time, parents' meaning efforts centred on talking with the child, engaging in sensory experiences such as smelling clothing, and reading the environment in such a way as to provide them evidence that their child was present and alright. However, parents had no genuine energy or capacity, or even proclivity to direct towards making meaning.

6 Months – 1 Year

Emotional Experience

The latter half of the first year continued to be difficult emotionally for parents. Parents reported feeling sad, depressed, guilty, and isolated. Parents continued to engage their pain in ways similar to the first six months. Visits to the cemetery, sleeping in the child's bedroom, playing music or videos that reminded the parent of their child all served to engage their grief. Parents reported that they still cried frequently, were still trying to adjust to a new daily routine, and trying to find new ways to fill the day. Anger towards the family members who were unable to provide emotional support remained. Patricia summarized her feelings about the lack of support felt from family, "And I think I was angry with my, at my parents and you know, certain relatives. Um, angry might have been a strong word, maybe more resentful? Maybe even deeper, like not as obvious as anger, more resentful maybe?" (February, 2004). Parents continued to struggle with the shattering of

assumptions about the world. Generally, parents felt that the pain would always be there and that it was unavoidable. Ron reflected on this relentlessness of grief,

It's just, you know, just like any healing I think...it doesn't happen in a straight line and, um, eventually you do start to, to feel some healing going on. But it's certainly a long time, and I don't think it'll ever, it'll ever leave me... I'll always miss him and I'll always have these feelings of um, anxiety or loneliness that comes with um, you know, that there's something not there anymore... (December, 2003)

However, there were some changes from the first six months. Parents reported a reduction of suicidal feelings, and less feeling of emptiness or feeling depleted. Therefore, the emotions that depleted the energy of the parent and robbed them of the capacity to interact and function in the world were changing such that they could begin to re-engage the world around them. This re-engagement was mitigated, however, by ambivalence for these external demands. Parents still didn't care for the things that they may have cared about previously, in part due to wondering what the point was to caring about something if it could be taken away.

In the first year, I would say probably the most profound change I would have had was that I no longer believed that if you kind of ... I no longer believed that good things would happen. And I also suddenly realized that I had no control over my life. That I thought I controlled it. That my thoughts, my actions, my words, controlled what would happen in my life. And there was a very profound realization that 'guess what gal, you ain't got any control!' You may be able to control some little nitty picky details, but the great

scheme of things is totally out of your control. And, (pause) you know, and anger...with that. You know, that, your, you know, your parents say, you know, just behave yourself and everything'll be fine! You know, so you behave yourself and everything's not fine, well then why the hell did I bother to behave myself in the first place? You know how many good years I screwed up there? (Nora, October, 2003)

In addition to their ambivalent feelings, the reality of the loss was also becoming more real to parents. "Coming to terms with, like his death was real now, like I didn't have that unreal feeling anymore. So it certainly seems to, from what I'm getting, it takes sort of one to two years where you still kind of feel it to be unreal." (Patricia, February, 2004).

Therefore, in the second half of the first year, parents continued to feel great pain. Despite the seeming relentlessness of their grief, parents were beginning to re-engage with the world. This re-engagement left parents feeling ambivalent about the worldly demands because they did not care about the things they had previously prioritized. The assumptions that were shattered continued to affect parents' emotional investment.

Coping Efforts

The shift from focusing on grief-related emotions to an awareness of other areas of their lives was beginning to occur. While parents still consciously engaged their pain, parents were beginning to be able to respond to work, other children, and their spouse, albeit without much enthusiasm. However, mobilizing coping efforts such as creating ways to honour their child, learning from their experiences, solving

daily problems, and reflecting on their lives actually decreased during the latter half of the first year. It would seem that the reality of the loss was settling in more so that any early efforts at problem- or emotion-focused coping no longer worked.

The second half of the first year seems to be a transition time between the old ways of coping and the gradual realization that these coping strategies may not work anymore. Parents realized that they could not continue to retreat from friends, family, and their demands and needs. Yet parents did not know how to act anymore and were consequently faced with a dilemma of experimenting with new coping strategies. This period is marked more by a realization that coping efforts may need to change than it is of overt changes.

Social Support

Parents noted that social support, both instrumental and emotional, began to diminish in the latter half of the first year. Parents realized that others' lives continued on and paradoxically, when parents were beginning to re-engage with others, those other people had stopped calling as often. The challenge for parents was negotiating the need to connect to others but concurrently feeling like a burden to others. Additionally parents felt like there was not much in common with their previous friends anymore. Despite these subsequent losses of support, parents deeply appreciated those who maintained contact, who let them talk freely, and who shared anniversary occasions.

Relationship with Child

Parents continued to be receptive to environmental cues and would interpret these as messages from their child. Nora described this ongoing receptivity to the

environment, "...and that can be as simple as a butterfly flying in front of you, or you know, when dandelions, those little puffy things that float around in the wind. Sometimes those things can be very profound for me. And that's when I was kind of 'well, thanks for the moment Grace', you know." (October, 2003). Parents also continued to talk with their child. These efforts seemed to sustain their role as parent. Thus, over the first year the child was very present in daily life.

Meaning Efforts and Outcomes

There was very little change in parents' capacity to create or find meaning as growth or benefit in their loss. There was, in fact, a slight decrease in parents' efforts. This would seem consistent with the emotional experience described above, whereby parents' early efforts at trying to be optimistic could not be sustained with the realization that their loss was permanent.

However, parents continued to try to maintain a spiritual connection to their child as described above. Parents felt that their spiritual beliefs buoyed them and helped them survive but their spiritual beliefs underwent an ongoing struggle as described by Carrie,

You either believe it or you don't. And sometimes you don't believe it. I know, I mean, I was adamant that I believed all these things, and then I remember coming into the room, having had like two hours by myself and went out for dinner, and I came back and I was driving back and just had this panic attack of 'Okay, no, I don't believe any of that'. (November, 2003)

Summary of the Second 6 Months

Emotionally, parents continued grieving deeply and constantly. Some of the emotions dissipated such as feeling suicidal. Parents began to feel some energy that could be directed to other people and activities; however, parents felt ambivalent about these demands because everything seemed so meaningless in light of their loss. Parents began to realize that they may need to cope differently but they did not have a full understanding of how to change or modify their coping. Finally, meaning efforts were centred on a struggle about what they believed and trying to receive some confirmation that their child was alright. Meaning efforts towards growth or benefit were still negligible.

1-2 Years

Emotional Experience

The reality of the loss seemed to settle in more deeply during this time as one mother described,

...as time goes on, that's the hardest. Two years pass, that's when it starts to feel real. It doesn't feel real, it just, it really doesn't feel real. Because what's real? I don't know what real is. But the fact that you don't get to see them after two years 'okay they're really not coming home' you know? (Carrie, November, 2003)

Parents still responded to their emotions in an overt way, however, the frequency began to decrease, "Um, I found that my frequency of crying lessened. Although when I did cry it was still as intense. Um, so rather than having sort of

these little melt down moments every week, they might be every month.”(Karen, February, 2004). Another mother described her experience,

Um, I think what happened is um, like I still had my periods of grief, but there was longer periods in between. And um, but I still remember like, like it’s almost like you’re sort of flat. Like you don’t feel a lot of joy and like you’re still kind of going through the motions. (Patricia, February, 2004)

Parents said that the myth that things would improve in the second year was probably the most difficult realization to accept. Most parents felt that the second year was worse than the first year. As these parents expressed the struggle of entering the second year,

And then I was having my friends and my family say you know, ‘Oh thank God you’re okay now’. And I kind of went (gesture of disbelief) And I don’t think anybody really knew the conflict, that, the turmoil... was going on inside of me at that time, where I was trying to present to the world, and there is an expectation from people, you know, there’s something magical in people’s thinking about the 1 year mark. You know, it’s been a year, you’re fine. Like, something magical happens the day after the anniversary date, you know? Like, where in fact, the second year of their grief is worse than their first, because some of that shock in them is just starting to wear off them at that point and they’re really starting to feel. (Nora, October, 2003)

You have your first month, your six months, your year. You always assume that that’s – you always hear people saying oh 6 months ‘Oh it’s bad!’ And

then like a year ‘Oh, that’s tough!’ And they say ‘But actually 2 years is worse’! I’m like ‘What’? (laughs) You’re very confused with that. You don’t want that to be the case. So, uh, for me it was that 2 ½ marker, and got through the third year and now I’m long into the fourth, and her birthday, which was a month ago was a fabulous day.” (Carrie, November, 2003)

Thus a new assumption about the process of grief had to be worked through. Parents believed that things would improve in the second year; however, as these mothers described, the second year is, in fact, very difficult. While some of the negative emotions decrease in frequency, the reality that the death is permanent, and that parents will live the rest of their lives without their child seems to be felt more deeply. The existential pain of being disconnected from previous roles, from others, and from beliefs seems to increase in the second year. The previous assumptions about benevolence, justice, fairness, and control now had a new group member. Consequently, parents continued to feel that their grief was unavoidable and they wondered if things would ever get better in light of this new realization.

There were some significant changes in the second year however. While parents realized that their pain was unavoidable, their energy for other things outside their grief was growing. Nora described the awakening of positive feelings,

So I think as you begin to process your grief, then you start to think, oh this thing happened and I’m really happy for that person, it’s kind of neat, I’m glad. So I think gradually you know, if, if you sort of envision it I guess as a glass full of water and the water’s your grief and as you start to process it that level of intense grief starts to come down, you can then fill the glass with a

few other things at the same time. I think that would be the best analogy I could maybe make of that. (October, 2003).

Parents felt that they began caring about things again, but the foci of their caring were different than before. While previous to their child's illness, they may have cared about material things for example, this no longer mattered. What now mattered was the quality of life. Very gradually, parents began to accept the reality of their loss and realized that they needed to survive. Nora went on to say,

I think I was becoming more comfortable with accepting that she would be a presence in my life and more comfortable with knowing that my goal was not 'to get over my grief'. That, sort of a realization was slowly dawning on me that this wasn't going to go away. I was hoping it was going to get a hell of a lot better but that it wasn't going to go away.

(October, 2003)

In the second year, parents had not expected that they could feel worse. Parents believed that things would start improving because they had passed all of the first anniversary dates of birth, death etc. When parents realized that they weren't feeling better, they felt betrayed again. Despite this, parents felt that they had more emotional energy for other things including exploring new relationships, feeling empathy for others, and spending quality time with family and friends.

Coping Efforts

Because parents were still feeling isolated yet also needing to be with others again, parents began reaching out to people. However, as many of their old friends had disappeared, parents sought new relationships often through involvement in a

bereavement support group. Many parents joined a bereavement support group during this time. The support group provided a unique opportunity of sharing with other bereaved parents. For one of the first times since the death of their child, parents felt validated, supported, and heard. Nora described the value of a support group for her,

The judgment's been taken away. Um, the validation of the feelings that you can't control circumstances in your life. Um, the understanding of my absolute paranoid fear of something happening to my son. That type of thing has been normalized for me. And that has been more supportive than anything else. (October, 2003)

Parents could finally talk infinitely about their child without risk of censorship or rejection. Other parents opted for one-on-one professional support and felt they received the same form of validation. Parents seemed to shift from 'being their grief' to 'living with their grief'.

Therefore, parents' capacity to re-engage the world seemed to initially focus on connecting with others. The challenge in meeting new people was whether to share their loss with the new person. Carrie described meeting a woman and the challenges of meeting new people when she initially showed her locket,

And I said, 'Yeah, it has Sarah my other daughter on the other side' and she's like 'Oh, you have another daughter?' And I said blah blah blah so I told her. And she just, she started to cry because her sister was dying of cancer who was 28 and we connected. And she was the only one I was able to connect with. And it was only because of that issue. Otherwise I would have had no

one in this group that really wanted to ever talk about my daughter.

(November, 2003)

In the second year, parents' coping efforts changed. In the first year, parents' coping efforts were focused on the emotional upheaval of their loss. In the second year, parents' coping efforts were centred more on reconnecting with others largely in an effort to feel validated. Parents began to seek out new friends, join a support group, and/or engage in personal therapy. Some parents also said that they read self-help books. For those parents who coped in the first year by "over-volunteering", they seemed to pull back and invest in a few personally meaningful activities.

Social Support

As can be seen above, coping efforts were largely centred on social support and connections during this time. While some parents continued to feel misunderstood by their family, most parents compensated by searching for support through other avenues, largely found through the support groups or professionals. Parents viewed these people as pivotal in the course of their bereavement.

Relationship with Child

Parents began to feel a form of separation anxiety in the second year. Ron described his ambivalent feelings about the change in connection with his son,

But it's a mixed feeling, because, when I feel a little bit of distance like that, I, I don't like that either. I want to grab on to the closeness that I felt before.

And it seems like, if there is an afterlife in the sense of our life, in our reality, it seems like he's farther away now. Like, he maybe stuck around for a while,

then he's off like, you know on Jupiter, whereas before he was just on Mars.

(December, 2003)

Additionally, some parents struggled in their connection with their child if they moved homes or went on vacation. Karen described how this changed over time, "Even though I moved out of the home, her home to here – she really does come with me. And there would have been a time when that was hard for me to do. Cause I thought I would be leaving her behind." (February, 2004). Parents still felt sensitive to dreams and the environment but the frequency of these cues seemed to diminish. Parents were moving to some belief or understanding that they would always have some kind of relationship with their child as Nora describes, "...and having an understanding that it was okay for me to continue to have a relationship with her. Even though she wasn't with me physically. Cause, you know, somebody dies, the relationship's gone, and this isn't true. I think by the second year I was starting to have this understanding that I would always have a relationship with her." (October, 2003).

Meaning Efforts and Outcomes

It would appear that the pivotal point for those who go on to make meaning as benefit or growth occurred around this time. Parents seemed to have reconciled their beliefs to some degree. Carrie says, "I was questioning all the things I believed and maybe I didn't believe that she's really here with me and all those things? So, yeah, I guess it did sort of change, it went up and down until I finally said, no, no I do believe this and I'm sticking to it." (November, 2003). Carrie's

comment attests to the ongoing struggle in trying to find meaning that will continue to be shaped.

During this period, parents confronted a cross-roads or T-intersection. They decided that they could no longer go on the way they'd been going. Carrie described her pivotal point where she realized that she had to change,

People would come over and try to, you know, try and cheer me up which doesn't work, right? (laughs) Sure, let's have a party, that'll work! (sarcastically) And I just said, "you know guys, I love you. I just don't feel like doing anything right now. You're just going to have to let me do this... there's nothing left in me." Oh God (whispers). So that was a big turning point for me. (November, 2003).

She goes on to say,

But yeah, I mean, depression is a, it's one of those stages I guess, right? So, if you have it it's a way of, you're either going to work your way up or you're going to stay where you are or go down. You go one way or the other, and I certainly wanted to. I kept saying to myself 'I'm so lucky for the life I have, I'm so lucky for the children I have. I knew that that was the way it is. I just couldn't feel that way.

Parents realized that there was too much to lose- family, spouse, job, and most importantly, the legacy of their child. They decided that they could not continue to be angry, bitter, resentful, or non-functional for their child; their child was not given to them to destroy themselves. Therefore, it was not for themselves that they wished to be better, but for their child. In this way, their role of parent was

retained. Nora said, “but it wasn’t centered on me. This is the big thing. It wasn’t centered on me. It was centered on Grace. It was almost like something I needed to do for her, as opposed to do it for me. I needed to do it for her”. She goes on to say about her choice,

Wanting to reach out and start to try to help some people. It was just kind of like a no brainer. But what it made me realize was that it wasn’t like that for everybody. So, you start to think well, why am I doing this? Well, maybe because it helps somebody. How can I do this? Well, maybe it’s Grace. Maybe Grace’s given this gift to me because I certainly wouldn’t have done this, you know, I’d maybe done volunteer work prior to that, if anything. (October, 2003).

The challenge of this juncture was that the parents realized that they did not know where it would lead, yet there was a renewed trust that it would lead to something positive. As a result, the lack of control they previously felt had been revised. Parents realized that they had some control over choices but there was now an awareness of vulnerability in the outcome. Karen and Patricia respectively, described their revised understanding of control, “And I realize to, again, to be patient, and to let things happen – naturally. You know, we can’t force everything all the time. You’re not in control (chuckles) of a lot of things. You know, we’ve got choices, but I find that when you sort of let go? Things will happen! (February, 2004). “Like I think you know, just with his death and getting back to this whole control thing, like I’m just so aware that your life can change on a dime! Like, I’m just really aware of that. (February, 2004). It was precisely because of that

vulnerability that parents began to engage the world differently. Parents began to appreciate their loved ones more, stopped taking things for granted, and more fully engaged in each day. This period marked the beginning of a life long change in their lives regarding their values and priorities.

Summary of the Second Year

This period seemed to be filled with choices and decisions. Parents who identified themselves as finding meaning chose to survive when they had felt suicidal, to live when they did not want to be around others or participate in the world, to take control despite feeling vulnerable, to find new friends when old ones disappeared, to trust the world that there was something meaningful when they felt betrayed by the world, and probably most importantly, to be a parent to their deceased child as well their living child(ren). This period marked the beginning of a life time commitment to leading a meaningful life.

2 Years and Beyond

Emotional Experience

The frequency and intensity of the negative emotions decreased after a few years but there was permanent access to the grief feelings. Parents realized that they could be thrown back to deep sadness at any time.

The sadness is always there. The emptiness is always there. The intensity of it, because of coming to peace with my life in general, is less. But, not all the time. There are times when you just can't get away from the intensity. Just because of something that happens – no one's fault, it's just, it hits ya, sort of

five minutes and you regroup and gather yourself back together and go from there. I, like, I really don't, I'm just quieter about it, then even I was before.
(Karen, February, 2004)

It may be that an anniversary holds significance or that some seemingly innocuous event occurs, "and the anniversaries are still really tough, but it was more the lead-up to it than anything? The only time I see it now sometimes is, and even not really this year, was just, before an anniversary of his death, all of a sudden I'd be like a mad woman doing all kinds of things, committing to everything, you know, the lead-up to that. (Patricia, February, 2004). But parents began to accept that their emotional lives would have an unpredictability and instability to it.

All this whole time? Up and down and that? Well yeah, it's really been up and down. A roller coaster. And that's a, that's a word that's been used a lot here in this room. Um, and we hate to feel that we have to do this but that's the way it is. You know, sometimes you feel okay, and sometimes you don't. And it's always something different that pops up in your head that makes you go down. You know? Yes, yep. And it's not something, I mean, I say I'm okay with that, but I'm not! Cause I hate being slipped off my feet all the time. (chuckles) But, I know it's going to happen again. (Carrie, November, 2004)

Assumptions about fairness, benevolence and the like, seem to have been worked through such that their beliefs about the world became more realistic. Parents now believed that you should take control where it is possible, there may be no understandable reason why some things happen to some people but that there is

undoubtedly some grander unknown reason, and life isn't always fair. Parents have been better able to accept the ambiguity of the world. As Carrie framed her beliefs, "I, I have to believe that there is something greater and that, uh, you know, there's a veil that I can't see her – she's right here with me and I have to believe that. That helps me to cope. If I don't believe that then I'm, I just sink". (November, 2003).

Parents experienced the return of more positive emotions particularly self-acceptance which in turn, developed their self-esteem. As Sophia reflected on the positive changes in her life, "but me feeling so much at peace in comparison to where I was before, so accepting of myself. That's a real gift that this experience has given me." (July, 2003). Where once parents felt judged by others and guilty, parents reflect back on their experience and their coping and how they have changed. Parents come to accept themselves with a certain pride. Patricia reflected on her coping, "Like, I look back now and I just kind of shake my head. I don't know how I did that, but I did!" (February, 2004).

Parents felt a certain hope and optimism for themselves and their future. In the early part of feeling some renewed optimism parents also experienced some guilt for these positive feelings. Over time, this guilt seems to diminish. Parents worried that by wanting to be back in the world, they had abandoned their child. Patricia described her struggle, "Well, because you've let go and you've moved on and a part of you doesn't want to let go and you want to hold onto it because that's – him. You know? (pause) And I realized to that I was feeling joy, like real joy? I had more energy, I was able to you know, do some studies and I did some certification courses." (February, 2004).

As the years go on, parents recognized that emotionally they are forever changed. While they can experience a range of emotions again, there is always an available road to grief. As they reflect on their lives, they realized that they have converted their feelings of inadequacy, being judged, and guilt, into feeling proud, competent, and confident.

Coping Efforts

Parents understood more deeply the paradox of control and feeling vulnerable; it has become a lived experience as Nora described, “But I think you gain that richness of experience with the recognition of the vulnerability. If I don’t enjoy this now, I might not get a second chance, because I could be struck by lightning tonight.” (October, 2003). This new sense of control affected daily decisions about the mundane and profound. Parents have taken control where they could, but have realized that they are vulnerable to the outcome- it may not turn out as intended.

Joan described her new understanding of control,

Um, in the beginning, um, it was kind of frightening because you spend your whole life thinking you can control everything and especially women, I think women tend to do that. Um, but, um, there’s a peace about it now, it’s amazing. So, and it’s taken me a while to figure that out. That there is peace in knowing you can’t control. (October, 2003).

Parents do not want to run anymore but want to be in their lives, appreciating others and the present. They have sustained a more problem-focused coping by reading relevant books, participating in valued activities, and choosing meaningful work.

Over the years, parents have developed ways to respond to their grief. Parents have realized that anniversary dates may disable them or they may not. Life will always have some unpredictability to it. Parents have learned a variety of coping responses depending on the situation, whether it be public or private. Nevertheless, parents have tried to regain a sense of control where they can and have invested their time, energy, and emotions into activities, people, and events that are personally meaningful.

Social Support

Parents continued to find and solidify relationships that were valued by them. They chose not to maintain friends for status reasons but only for intrinsic satisfaction. They continued to enjoy hearing stories about their child by others, as it told the parent that others have continued to remember their child. There was an ongoing disappointment, however, with those who were unwilling to talk about their child. As Annette explained why she likes to hear her child's name, "Um, whereas I think some people have a difficult time when you even mention the fact that they lost a child? Um, it's hurtful at times. But I need – it's a way of keeping that relationship going. It's a way of keeping her you know, alive in a sense. In my life." (February, 2004). Parents seemed to be sensitive to same-aged children as the years passed and continued to enjoy hearing from their child's friends. Oftentimes, the bereavement support group had ceased but its effects were found in other ways. Some parents carried those skills to help others, while others volunteered for children or elderly persons. Nora described her passion for her work,

Um, but on occasions we'd go out and tell my story as a means of helping other people and role modeling survival, and thinking to myself later, you know, she's been dead for eight years, and yet tonight her story still helped somebody. How profound is that? Because when I've been dead for eight years, probably nobody'll remember who the hell I was. (October, 2003).

The support derived from the group or professional or family member or friend has facilitated the parent's self acceptance which has in turn, enabled the parent to find a peace and compassion for others. Thus, all meaning outcomes reported by parents have been social in nature.

The social support experienced over the years changed from emotional and instrumental support in the first couple of years, to a quiet kind of emotional support over the years. Parents deeply appreciated when others remembered significant anniversary dates and when people shared stories of the child. Parents acknowledged that any person who could continue remembering dates and the child over many years was a special person. These were the kinds of people that parents wanted to be with; people with whom they felt they could share their deep and sometimes complex emotions.

Relationship with Child

Over the course of years, parents change their relationship with their child. They retained the role of parent in that they needed to believe that their child was alright and in a better place and that they will see their child again. But a new relationship began to emerge. As was evident during the child's illness, parents began to relate to their child as one who has wisdom. Parents reported talking out

loud or in their head, and asking for guidance or talking to their child about topics they may not have if the child were alive. Frank described this change in his relationship with his daughter, “maybe I tried to talk to her or related to her still as a father/daughter but, I guess it’s a little bit different, because, if you go there [to the cemetery] and talk to her, then, you’re relating some of your everyday stuff, and maybe some things that you might not if she was here.” (October, 2003). Carrie said, “I still talked to her and stuff, asked her questions and whatever. I mean she never answered.” (November, 2003).

Parents felt that over the years the child’s presence was always felt but changed in frequency and intensity. Elizabeth wrote, “She never left me. We communicated in my thoughts. She is with me. I am reminded of her when I go to certain places or have other experiences. She is still with me, nearly 15 years after her death, only by now she is less noticed by me. She is just there.” (January, 2004). Sophia adds, “I would say it’s only been in the last few months [6 years after his death]. Up until then, I think he was still out there. I feel him part of me. I can’t tell you how I feel him part of me. It’s so powerful to tell you this” (July, 2003).

As will be described in the next section, parents also decided that they wanted to ensure that their child’s life and death had and continues to have, meaning. As a result, parents struggled to find ways to create a legacy. Therefore, over the years, parents retain the role of parent by ensuring a legacy, but they also view their child as wise and ask for help and guidance in their life choices.

Meaning Efforts and Outcomes

The cross-roads discussed earlier that had set into motion a life course continues to unfold over the years. Most parents predict that it will be with them until they die. As Carrie so eloquently summarized her expectation that she will not understand the greater purpose of her life until she dies,

I think yeah, when I'm dying (laugh together). That's just going to happen. I figure that's when, you know, cause once you get it, then what's the point? (laugh together) Why would you hang around here and suffer? Forget it...So, yeah, I think it's going to go on for ever, but if I compare who I am or how I feel about myself from 10 years ago, I, I have leaps and bounds – definitely yeah, so it's a good thing. Um, it seems like a lot of work. It's, sometimes you go, oh, come on, just (chuckles) make it easy for me! But, that's the way it is, and, and I'm determined to continue on that path. I think when a person dies, or when your child dies, um, you have to be, somehow you have to get into that analysis because, it doesn't make sense, you know? It's not right. So there has to be a deeper meaning in your life, or else what's the point? Why would a child die? You know? (November, 2003)

Efforts to actively make meaning and the outcomes of these efforts increased dramatically after two years but many parents admitted that it takes more than 4 -5 years for those genuine efforts to occur. One of the primary outcomes was increased self-acceptance and improved self-esteem. Self-acceptance enabled the parents to participate in the world in a different way from before their child's illness. By accepting themselves, the parents have incorporated their child's life

and death into their identity; it is now part of their story. The parent retained the role of parent and wished to be a better person for the child. Self-acceptance permitted parents to make choices about their friends, their careers, their activities, and their spirituality. Their choices were bound less to status or what others will think. As Nora described the evolution of her priorities,

I gotta go back to work, but, I really don't care what I do, cause who cares? My child's dead. Who, like who cares! So, I, I think, part of that change in value comes from the not caring, to...that eventually changes to a change in priorities - that there are things that you do care about, that you feel that there're now much more important things to care about than what there might have been before your loss. You, you move from not caring about anything to desperately caring about things. Um, but they're different things than you cared about before your loss. They tend to be much less materialistic than you cared about before your loss, which was, you know, how new is my car, how nice is my house? Um, to how safe is my child? How much happiness does this give me? (October, 2003)

Other meaning related outcomes reported included a deepened spirituality, greater capacity to listen to others, heightened sensitivity to others' situations, deepened relationships with others, greater appreciation for the present and what they have, and acceptance of themselves and others. Patricia described her involvement with others, "Yeah. And I still revisit it a bit um, I guess through this mother's group as well. Like one of the mom's now, her son's dying so, so I revisit it sometimes. But that's not a bad thing anymore. Like it's sad, but, like I feel good

that I'm helping someone.”(February, 2004). Parents admitted however, that to find or create meaning, it was necessary that one sink down in the depths of grief beforehand. As Carrie described the effect her depression had on her, “Sense of self has changed. Yeah, well again, the depression did that for me, because um, I am moving toward being the best that I can be now”. (November, 2003)

Summary of Two Years and Beyond

Parents felt that emotionally, they were always vulnerable to situations and people and that that would not change. Parents' range of emotions returned though maybe not with the same high points as before the death. Parents made a decision to take this experience and create something positive from it in an effort to honour their child. Parents' relationship to their child grew to be a bit more complex where the parent retained the role of parent, but they also viewed their child as being wise and so parents sought guidance from their child. Their child's life and death catalyzed a life course that affected the parents' values, priorities, relationships, and investments. The people around the parents were chosen for qualities that were consistent with the parents' new values and priorities. All of these changes affected the parents' sense of self and self-esteem in a positive way.

The above description has used the themes to describe their unique contributions to the meaning-making process. However, as I am sure was evident, these themes are not independent but inter-dependent. Therefore, in the next section I will attempt to weave the themes together over time.

The Inter-relationship of Themes over Time

In the first year after the child's death, parents experienced a mix of negative emotions such as sadness, anger, resentment, and suicidal feelings combined with a decrease in energy described as black, half-dead, and empty. Parents found it difficult to function in their previous way and relied on others to help with daily chores. This support decreased within the first year and consequently, parents felt isolated and misunderstood. This social isolation undoubtedly compounded their intense feelings of separation from their child. Parents were very receptive to any cues that they could define as a message from their child and so their physical and emotional energy was often directed at their relationship to their child.

Consequently, outside expectations were met with ambivalence. Parents' efforts at establishing some kind of connection with their child contributed to their struggle to find meaning. Very little effort was directed at trying to make sense of the death as efforts at trying to make sense were explored more deeply during the illness.

Parents seemed to move quickly into a spiritual questioning. The first year, then is dominated by paradoxes: parents felt grief intensely but also numb; parents received a tremendous amount of support but they could not receive it as it was intended; parents coped by confronting their grief and then by avoiding it; and finally, parents were receptive to any cues from the environment that told them their child was alright but were also questioning their spiritual beliefs.

In the second year parents were initially surprised that they actually felt worse when they thought they were supposed to feel better. There were social expectations that they should be 'moving on'. Parents seemed to hit a cross-roads

around this time when they realized that they could not continue functioning in their current manner. Parents began to reconcile their spiritual beliefs, which seemed to re-establish some benevolence in the world and in God. This spiritual reconciliation seemed to open the parent up to making different life decisions. In turn, parents began to feel better about the world they lived in.

This choice point set into motion the decision to be a better person and honour their child despite not knowing how this would occur or where it would lead. Therefore, parents seemed to gradually move from finding meaning to making meaning. Parents moved from being receptive (finding meaning) to the environment which parents felt were signs from their child and seemed to address a spiritual meaning, to being active in the environment (making meaning) which facilitated their meaning as growth or benefit. Parents began to seek support usually in the form of a bereavement support group or professional support. This helped to validate the parents' experience and feelings. This support seemed to also enhance the parent's positive emotions and allowed them to begin to accept themselves and their limitations.

In the following years, parents who defined themselves as making meaning, mobilized their choice faced at the cross-road and made choices about how this meaningful life would be lived. Parents made choices about friends, where to invest energy, and how to create a legacy for their child. Ultimately, parents came to some self acceptance and enhanced self esteem not felt prior to their child's illness. This change manifested itself in socially driven acts of helping others, feeling more compassion for humankind, accepting a greater power, and being

driven to create a legacy for their child. Before this could occur though, parents stated that it was necessary for them to sink down in their grief first. Therefore, they felt that the negative emotions served a purpose in the course of meaning-making.

Meaning-making as benefit or growth is a complex process that involves a host of interdependent factors. Through the course of time, these factors interact, facilitate, and inhibit the process of meaning-making. Throughout this process, parents experienced the highs and lows of these decisions, feelings, and social relationships. For these parents, decisions were ultimately made that facilitated their meaning-making that these parents say will continue until they die.

Themes by Time

Creswell (2003) states that quantifying the qualitative data can confirm the prominence of the themes. Therefore, an additional analysis of the qualitative data was performed. The five themes of meaning, emotional response, social support, coping efforts, and relationship to the deceased child were analyzed for their frequency across time. The interviews were divided into the time frames of the first six months, first year, second year, and beyond two years. Each of the five themes was then tabulated for frequency of occurrence in each of the time frames.

Table 2 describes the number of parents who described their meaning efforts. As can be noted, parents made some early efforts which would relate primarily to their spiritual meaning search while it was not until two years and beyond that parents really began making efforts towards making meaning as it relates to benefit, growth, and purpose. The efforts towards meaning-making show a marked increase over time.

Table 2

Parents who Discussed Meaning Efforts/Outcomes across Time (N= 16)

	Time Intervals			
	1 st 6 months	1 st Year	1-2 Years	2+ Years
Meaning [*]	6	6	8	14
Meaning Outcome [†]	7	5	9	15
Honour Child [‡]	5	3	6	10
Journey [§]	1	0	6	2
Personal learning ^{**}	2	0	2	3
Make sense ^{††}	2	1	1	2

* Life's purpose, "why"?-spiritual; changes in behaviours, priorities

† Caring, sensitive, live each day to the fullest, teach others

‡ Legacy; way to keep memory of child alive

§ Ongoing process; one that will continue

** Willing to be challenged, necessary

†† Fits/doesn't fit with assumptions about the world; try to find an explanation

Table 3

Number of References to Negative Feelings across Time

	Time Intervals			
	1 st 6 months	1 st Year	1-2 Years	2+ Years
Physical Pain ^{††}	5	5	2	1
Emotional Pain ^{§§}	106	69	41	25
Existential Pain ^{***}	28	11	15	20
Decrease in energy ^{†††}	33	15	6	10
Cognitive ^{†††}	26	16	2	8
Constancy ^{§§§}	16	10	7	7
Other-oriented ^{****}	20	5	18	10

^{††} Feel sick, physical pain

^{§§} Hurt, crying, misery, suicidal, hole, rock bottom

^{***} Longing, disconnected, isolation

^{†††} Half dead, frozen, paralyzed, depleted, helpless, empty

^{†††} Confused, closed down, numb, unreality

^{§§§} Always be there, unavoidable

^{****} Judged, isolation, misunderstood, lonely

Tables 3 and 4 respectively summarize negative feelings experienced, and positive feelings and states experienced. The negative feelings were sub-categorized into seven broad categories of a) Physical pain which reflected parents' description of feeling physically ill; b) Emotional pain which summarized crying, anger, and feeling suicidal; c) Existential pain which focused on parents' feelings of disconnection with themselves, their families, society, and their child; d) Decrease in energy which described parents' inability to function in their previous ways because of their lack of energy; e) Cognitive aspects which addressed parents incapacity to think clearly, follow instructions, and feeling numb; f) Constancy of the negative emotions which summarized the parents' belief and sense that they would always feel deep sorrow and pain; and g) Other-oriented which focused on the parents' feelings that others were judging them for how they were grieving or that they were misunderstood by others. Table 3 demonstrates that emotional pain is the type of pain most often expressed by parents and that emotional pain is most acute in the first year with a steady lessening of the negative emotions over time. This table clearly shows that in spite of the meaning efforts seen above, emotional pain remains though some facets of this type of pain lessen with time. The idea of constancy, existential pain and feeling misunderstood however, continue more or less steadily.

Table 4 summarizes the positive feelings and states expressed over time. Self-acceptance was the most often cited change by parents. The narratives described this gradual shift towards greater self-worth and self-acceptance and the table demonstrates this gradual shift over time. Concurrently, greater experiences of

other positive feelings and states such as feeling more receptive, compassionate, and peaceful also occur more often over time. Both these tables confirm that for the most part, negative feelings lessen with time though some remain and that positive feelings gradually emerge as the negative feelings give way.

Social support is summarized in Table 5. Parents discussed social support in relation to their family, friends, colleagues, and community. Additionally, a few parents described that there was a pivotal person to whom they credit responsibility for helping them shift their grief focus from sadness only to searching for meaning. Oftentimes, this person was a professional but the key feature of this person was that the parent felt validated by that person. For the most part, social support from family and friends is perceived fairly consistently across time. Community support, usually found in the religious community, drops dramatically with time. The pivotal person seems to emerge after two years which is consistent with the time at which parents experience more positive feelings and embark on meaning efforts. Professional support and group support gradually increase but overall remain consistent. Most parents lessen their involvement with each of these support sources as time passes. All parents reported some type of negative response from others at some point during their bereavement. This table shows that the negative reactions occur most often immediately after the death, but that there remain challenges over the long term.

Table 6 summarizes emotion-focused and mobilizing coping efforts over time. Approach-based emotion coping strategies in the form of going to the cemetery or

Table 4

Number of References to Positive Feelings and States over Time (N=16)

	Time Intervals			
	1 st 6 months	1 st Year	1-2 Years	2+ Years
Self acceptance ^{†††}	15	15	24	22
Positive feelings/states ^{††††}	12	9	6	20

^{†††} Self acceptance, self-worth, Be myself

^{††††} Receptive, compassionate, at peace

Table 5

Social Support References Reported by Parents (N=16)

	Time Intervals			
	1 st 6 months	1 st Year	1-2 Years	2+ Years
Positive support				
Family	12	9	10	9
Friends	11	7	8	11
Colleagues	3	1	1	3
Pivotal person ¹⁶	2	0	2	5
Community	6	5	0	1
Professional/Group support				
Professional ¹⁷	8	5	7	9
Support Group	5	4	6	7
Non-support/Negative response				
Non-support ¹⁸	10	7	3	4
Social support challenges ¹⁹	7	3	6	3

¹⁶ Person defined as instrumental in helping them through their grief- professional or personal¹⁷ Doctor, Minister or any individual for whom the relationship was defined as professional¹⁸ Person offered no help when the parent thought they would receive support from them¹⁹ Remarks that were insensitive, hurtful

staying in the child's room decrease dramatically with time. Avoidance-based strategies such as denial, and going away are reported more frequently than approach strategies but avoidance strategies also decrease with time. However, avoidance strategies are consistently reported with more regularity over time. Problem-focused strategies or mobilizing strategies such as care for others, self-care and journaling are used throughout the process fairly consistently.

Finally, Table 7 summarizes parents' changing relationship with their child over time. This category encompassed parents' descriptions of feeling the child's presence, talking to the child, and living through other same aged children. This table shows that parents maintain a relationship with their child over time.

The qualitative data analyzed from this perspective confirms the narratives of the bereaved parents. Meaning-making efforts towards growth and benefit do not seem to begin until the second year and gain momentum after that time. The negative emotions prevalent in the year after the death diminish in frequency but can still be felt with great intensity over time. The positive emotions seem to emerge concurrently with mobilizing coping efforts and connecting with pivotal people. And finally, parents continue to make efforts to maintain a relationship with their child.

Table 6

References to Coping Responses over Time (N=16)

	Time Intervals			
	1 st 6 months	1 st Year	1-2 Years	2+ Years
Emotion-focused				
Approach ²⁰	26	20	13	4
Avoidance ²¹	69	40	26	17
Mobilizing/Problem-Focused coping ²²	58	34	53	46

²⁰ Engaging emotion such as anger

²¹ Avoidance of emotions such as denial, go on a trip, retreat from others

²² Humour, care for others, hope, rebuilding, self-care, journaling

Table 7

References to Relationship with Deceased Child (N=16)

	Time Intervals			
	1 st 6 months	1 st Year	1-2 Years	2+ Years
Relationship with child ²³	48	34	38	23

²³ Maintenance of connection through observing same age children, reading events in natural world as symbolic of child, talking to child

Negative Cases

As mentioned in the Method section, some negative cases were noted. The above description suggests that reconciling spiritual beliefs was an important element to the process of meaning-making for most of these parents. Reconciliation of the spiritual dimension seems to open the parent up to directing energy to meaning-making efforts that are evident in choices of friends, values, activities, and work. However, one parent reported that she had no spiritual beliefs and did not believe in God or any of the environmental cues that parents valued as communications from their child. Interestingly however, she did say that she chose friends who were believers and she continued to be very involved in her religious institution. She was also the only non-Christian parent interviewed. Therefore, a more diverse sample of ethnicity and religion may help to understand this apparent middle phase of meaning-making whereby, the parent comes to reconcile that they believe in a greater power that is benevolent.

Another negative case relates to the value of the support group or professional support. As was described above, parents who were interviewed felt that the support group gave them unique opportunities of feeling heard, understood, and validated. This confirmation seemed to move parents forward in their acceptance of themselves and their struggles. Through this acceptance, parents seemed to choose new friends and partake in new activities that moved them forward in their meaning-making. There was one parent interviewed who did not attend a support group nor receive personal professional help, however. In her description, she instead derived a great deal of support from her religious community and from her

friends who had also lost children. She was from a small community and so any child deaths were known to the other community members; therefore, she felt that she received a significant amount of personal support and validation from this community and from other bereaved parents.

Her description raises the discussion of the value of support. For most of the study participants, they could not rely on a local community and needed to go to a ‘specialized’ community of bereaved persons. One mother attended a support group in the first three months after her child died and she was the only parent who reported that the support group was not helpful. She reflected on the reasons for her feelings and stated that she felt it was premature to hear other parents’ stories while she was so intensely grieving the death of her daughter. Additionally, the facilitator’s name was the same as her daughter’s which she found distressing. By the second year this mother found support and validation through personal therapy. These cases emphasize the unique experiences of parents’ journeys in meaning-making. In both of these mother’s cases, they found the validation and support they needed. However, a future study of the variety of supports that serve similar purposes would be worthwhile.

DISCUSSION

Summary

The main purpose of this study was to contribute to our understanding of the process of meaning-making for parents who have lost a child to illness. The intention was to address the lack of descriptive information on the process of meaning-making. Current literature on bereavement has focused more on the

process of bereavement, with the more recent literature addressing meaning outcomes, but very little has described the meaning-making process itself.

Rich information was derived from the interviews and qualitative portion of the questionnaires. This procedure allowed parents to describe their experiences over the time since their child died. As mentioned in the Method chapter, the qualitative data were analyzed using both a computer-based qualitative analysis program and manually. My summary of the findings was then returned to a representative sub-sample of 6 parents who provided feedback on the accuracy and wording of the process. This procedure is considered a validity check. Suggestions were then incorporated into the final version of the description of the process.

Overview of the Process of Meaning-making

Through analysis of the qualitative data on 16 bereaved parents and the more in-depth descriptions from 13 of these parents, I described a process of meaning-making that emerged as a result of the loss of their child to illness. Briefly, parents experienced the more commonly reported experiences of bereavement in the first two years but at some point after the two years, these parents made some different choices about how they were going to cope with the loss of their child.

Specifically, parents chose to make some meaning or find some benefit or sense of purpose from the loss of their child after reconciling some of their spiritual beliefs. Commonly, the study participants decided that they could not go on living with such pain, anguish, anger, bitterness, and sorrow. While they agreed that they would still have moments of these painful feelings for the rest of their lives, they wanted to create a legacy for their child and this legacy would transform the

parent's values, behaviours, interests, and social interactions and self-esteem. Additionally, participants found greater value in their personal relationships and experienced greater self-worth than prior to their child's illness. It was this departure from the traditional models of bereavement that seemed to define these parents who described themselves as having found meaning from their loss and through their bereavement.

The following discussion will review the literature on social support, relationship with child, and meaning-related literature in relation to the current study. Then, as noted before, because little research relates findings to current theoretical models, findings of this study will be considered in light of the Meaning-reconstruction Model and the Dual Process Model.

Social Support

Participants in the current study said that they experienced a variety of social support over the years. Most participants felt that friends were the primary supports while family support was viewed with more ambivalence. Participants usually felt let down by their family. Parents felt constrained in their grief because they could not talk about their child to their family. Despite this, family provided the instrumental support that parents valued especially in the early weeks and months after the child died. Participants reported that personal support diminished dramatically over the first year and regrettably, this paralleled parents' need to reconnect with others. Consequently, participants often turned to professional support in the form of a support group and/or personal therapy. The sense of validation derived from this interaction proved to be pivotal in the course of their

grief and meaning-making. Parents began to seek new friends or reconnect with old friends with whom they had shared values and beliefs.

One of the key identified risk factors in bereavement was the availability of social support. Again, the literature focuses more on spousal loss; however, some studies have looked at the effects of social support on grief outcomes for parental loss. Studying parents who lost children to a violent death, Murphy, Johnson, Chung, and Beaton (2003) found that perceived social support predicted the parents' change in post-traumatic stress disorder (PTSD) symptoms over a 5-year time frame. Therefore, those who perceived greater social support experienced greater decreases in self-reported PTSD symptoms. Lepore, et al. (1996) studied women who had lost an infant to sudden infant death syndrome (SIDS). Specifically, they looked at women who felt socially constrained as measured by a 10-item scale they developed against discussing their child's death and the effect of such feelings on depression and intrusive thoughts. Questions on their social constraints scale asked questions that related to how often and how openly the mother felt that she could talk about the baby's death. They also asked how much the mothers desired to talk about the infant's death. They found that women who felt socially constrained, experienced more intrusive thoughts and depressive symptoms up to 18 months after the infant's death. Conversely, women who felt less constrained against discussing their deceased infant, exhibited fewer depressive symptoms and intrusive thoughts over time. They postulate that by reducing opportunities to discuss their child, mothers cannot process the loss and thus, cannot emotionally adapt to it. This is consistent with Miles and Demi (1991-92) who

found that loneliness was the most distressing aspect of parental bereavement. Nolen-Hoeksema and Davis (1999) found however, that ruminators, as measured by the Response Styles Questionnaire (Nolen-Hoeksema & Morrow, 1991) who were bereaved by a family member dying of an illness were more likely to seek support than non-ruminators. When ruminators felt emotionally supported they were less distressed 18 months post-loss.

In a comparative study, Sanders (1979-80) found that parents reported significantly higher levels of grief than spouses and that the parents reported an obsessive ruminative questioning of 'why'. Thus, the need to talk or to feel supported by others may be more prevalent in bereaved parents. The challenge for family and friends however, is that the loss is non-normative and thus, many bereaved parents felt that their loved ones found it difficult to provide support, specifically, from family. Lehman, Ellard, and Wortman (1986) suggest that family may be unable to support bereaved spouses and parents because they may feel more responsible for alleviating the pain or distress and may be more motivated to see the bereaved person "recover". Additionally, Lehman et al. also found that bereaved individuals experienced a variety of unhelpful or hurtful statements that were commonly categorized as giving advice about how to feel or grieve, encouragement of recovery, minimization or forced cheerfulness, and identification with feelings when they had not shared a similar loss. Consequently, many bereaved persons sought support in a bereavement support group. Also, as was evident, parents conceded that they were inconsolable, particularly in the early period after the loss. So while some parents reflected later that others had good intentions, at the time

immediately after the death, there was nothing a person could say to make them feel better.

In this sample of bereaved parents, 11 of the 16 parents sought support through a bereaved parents' support group while two of the remaining parents sought individual professional support. Most parents heard about this study through their contact with the bereavement support group, so the sample is skewed towards parents seeking and deriving benefit from this form of support. Parents reported that their involvement in the support group was a pivotal point during their bereavement. It was in this environment that parents felt heard, validated and supported for one of the first times.

A few studies have looked at the effects of support group involvement in bereaved parents. Klass (1984-85) states that bereaved parents find support in a group of similarly bereaved parents because it entails a unity, and the experiential quality of helping others, in turn helps oneself. Reilly-Smorawski, Armstrong, and Catlin (2002) found that a support group offered to parents whose child died in the neonatal intensive care unit provided parents an opportunity to discuss feelings that were specific to that experience. Geron, et al.(2003) concur with Klass when they looked at parents' motives for joining a group and their interpersonal relations in the group. The most significant motives for joining were a desire to meet other bereaved parents, to develop better coping skills, and a desire for contact with professionals in bereavement. They also found that the parents whose primary motive for joining was to have contact with others in the same situation were more likely to perceive that participation in the group positively contributed to their

adjustment.

However, the evidence for the effectiveness of bereavement support is mixed. Murphy and colleagues (1996, 1998, 2002) found that for bereaved parents whose child died as a result of a homicide, suicide, or accident, there was a positive relation between their initial level of distress and PTSD and support group participation. Specifically, those parents who initially presented with higher levels of distress were more likely to become involved in a support group. However, involvement in the support group did not influence the parents' reduction of symptoms of PTSD. Retrospectively, however, parents reported that their involvement in the support group was pivotal. One explanation that the authors provide for the discrepancy in parental reports is that there are limits to recovery, meaning that nothing may help. This was a consistent finding in the interview whereby parents stated that no matter what a support person said or did, it could not take away the pain. This was also true for the mother who sought support through a bereavement support group in the first three months after her child died. She felt that the group was not helpful during this time.

In comparison studies there is some evidence that the suddenness of the loss precipitates unique bereavement experiences compared to those bereaved after a lengthy illness which may affect the contrasting results for the PTSD symptoms found by Murphy. Shanfield, et al. (1986-87) found that parents whose adult children died from a car accident were more distressed compared to parents whose adult child died from cancer. Miles and Demi (1991-92) found that parents whose child died from accident or suicide experienced more guilt feelings than those

parents whose child died from a chronic disease. Sanders (1982-83) did not find statistically significant differences among those whose family member died suddenly or after a chronic illness, but there were trends. She found that the group whose family member died suddenly tended to maintain an internalized emotional response which seemed to create a prolonged physical stress while those bereaved after a long-term illness tended to feel more dejected, frustrated, and lonely. Therefore, in relation to the Murphy PTSD studies, it may be the unique grief outcomes which a sudden loss precipitates may have negated some of the positive effects of the support group.

Another explanation for why parents may construe the support group as a positive influence comes from a study by Davis and McKearney (2003). In a series of three studies, the authors investigated students who had experienced some sort of loss or near-death experience. They concluded that finding some positive in a negative event may initially serve to protect oneself from a variety of fears, but then later, this positive reframing may help towards affirming oneself and one's worldview that may be more elaborate though just as positive. Davis and McKearney's study may relate to the findings of another of Murphy's studies (Murphy, Johnson, & Lohan, 2003). In that study they focused on meaning-making and found that those who participated in a support group were significantly more likely to find meaning than those who did not attend. These studies distinguish the importance of outcomes when considering what to measure in bereavement studies. The current study of parents who defined themselves as having found meaning largely felt that the support group was a pivotal part of their adjustment. This type

of validation helped them move into a period of beginning to positively (re)appraise their life, values and decisions. This experience is confirmed by Cadell, Regehr, and Hemsworth (2003) who found that bereaved HIV/AIDS caregivers experienced more growth if they reported more social support. They also found that the greater the stress the caregivers experienced the more growth was reported.

Additionally, the above studies suggest that there are unique experiences depending on the age of the deceased, the relationship, and the type of death whether it be sudden, violent, or from illness. More research into bereaved parents who have lost a young child suddenly or after a lengthy illness may help to clarify some of these discrepant findings.

Neimeyer (2000) provides a number of recommendations for those providing grief counseling. He advocates that the counselors facilitate the bereaved person's efforts to find meaning and not to necessarily offer grief focused sessions. In his review, he found that grief counseling works better for those experiencing traumatic grief (of which the loss of a child is considered traumatic), and for those experiencing prolonged grief than for those experiencing a normal grief. Thus, it behooves the professional sector to consider these variables when either providing or referring for therapy, particularly since bereaved parents found that family was ineffective in providing the support they needed and wanted.

Relationship with Child

The evolution of the parents' relationship with their child was an important part of parents' process of meaning-making in my study. During the child's illness, parents seemed to experience two types of relationships: being "super parent" and

being the “student” to their child’s wisdom. During the early phases of bereavement, parents tended to focus more on their role as parent whereby parents desperately needed to know that their child was safe and alright. Over the course of time, a resumption of the relationship of learning from the child emerged. It would seem that once a parent moved into making meaning, parents continued to negotiate this dynamic between retaining the role of parent, but also seeing the child as wise and therefore, someone to whom the parent could turn for guidance.

Arguably, the parent-child relationship is an intense, complex, and highly meaningful relationship (Bowlby, 1969, 1973, 1980). Therefore, to create meaning from such a significant loss could be construed as impossible. However, this study and others (Cadell, et al., 2003; Craig, 1977; Lehman, et al, 1993; Murphy, Johnson, et al., 2003) have shown that it does occur. Weiss (1988) concurs that any threat to the child “evokes extremely high levels of protective energies” (p.41) and when a parent’s efforts at protection have ‘failed’, parents can be left feeling helpless. Parents in this study struggled with early feelings of guilt, of not having done enough but over time, they came to reconstruct those early efforts more positively and looked back on themselves with compassion and even awe. Milo’s (2001) mixed methods design studying the experiences of mothers who had lost a disabled child, also found that mothers struggled with shattering of assumptions at their child’s diagnosis of a disability and then again at the child’s death. Mothers reflected on their experiences, weighing the challenges and gains, the joys and the sorrows and seven of the eight mothers concluded that it was an experience they would never give up.

Few studies have really considered the experiences prior to the death in relation to after the death in terms of the parent's experience. Rando (1983) and Sanders (1989-90) were two of the few who looked at this and found that a mother's intense involvement in her child's care over a prolonged period of time negatively affected her grief in that these mothers were more likely to ruminate over the death. The current study does not have the capacity to compare whether these parents ruminated more or not. Most parents felt that it was impossible not to think about their child's death in the early part but whether this was excessive cannot be determined. Nevertheless, parents all reported that the frequency of thinking about their child lessened with time and the thoughts about the child shifted from focusing on what wasn't done in the past, to what can be done in the present and in the future in their own lives.

Klass (1993, 1997, 2001) conducted a 10-year ethnographic study of a chapter of Compassionate Friends, a bereavement self help group. He concurs with my study in that parents concede that the feeling of loss can never be fully healed. He coined the term "inner representation" of the child which he says is represented by a sense of the child's presence, sensory hallucinations such as smell, beliefs that the child actively influences events or thoughts, and a willful incorporation of virtues of the child into the self. As was shown previously, parents made mention of all these activities. In the early days, parents were receptive to these environmental cues while later, they also made active efforts to incorporate aspects of the child or perceptions of the child into their more philanthropic activities and values.

Redefining the relationship with the child was an important aspect in the

process of parents' meaning-making. By feeling that the child was in a better place, that they would see their child again, by constructing experiences to maintain the relationship with their child, and by seeing their child as a guide to facilitate their choices about meaningful actions and values helped parents in their process of meaning-making.

Meaning-making

As mentioned above, previous research has acknowledged that positive outcomes can occur after a significant loss; however, the process has been far less documented. Contributing factors such as relationship with child, social support, and spirituality have often been considered independently. This study has described how these factors change over time and how they affect one another. It has also been noted that studies measuring meaning over time use only a 1-item question that often combines the terms "make sense" and "find meaning" (Boerner, Wortman, & Bonanno, 2005; McIntosh et al., 1993; Murphy, Johnson, et al. 2003). My study identified a number of important factors that seemed to facilitate parents' movement towards meaning as benefit, growth and purpose: social support, the value of positive and negative emotional and cognitive responses, the relationship with the child, and the relationship to their emerging spiritual beliefs. As well, parents reported shifts in meaning focus from making sense prior to the death, to existential search for meaning which seems to be related to finding meaning (Attig, 2001), to making meaning in terms of growth, benefit, and purpose.

Parents did not seem to engage in the making-sense process after the death that Davis et al. (1998) described. The participants did mention that this was part of

their process at the time of their child's diagnosis. We may speculate that having a seriously/terminally ill child is the first shattering of assumptions that propels the parent into this early questioning. Consequently, after the child dies, parents do not necessarily return to this effort at trying to make sense. Because they could not make sense of the diagnosis, parents seemed not to re-engage a futile line of questioning. Instead, they seemed to move into a more existential questioning that parallels Frankl's (2000) understanding of a search for meaning. Parents deeply probed their beliefs, their faith, their religion, and their spirituality. During this questioning, parents also seemed to construct experiences in the environment to symbolize the presence of the child as described above which relates to Attig's (2001) idea of finding meaning. Most parents eventually came to a belief that there was an afterlife, there was a benevolent God, their child was safe and guiding them, and they would see their child again.

Moskowitz, Folkman, Collette, and Vittinghoff (1996) found in a path analysis that spiritual beliefs facilitated positive reappraisal which in turn helped maintain positive psychological states. McIntosh et al. (1993) also found that parents bereaved from SIDS who participated more in religious services reported greater amounts of social support and reported finding meaning in their babies' deaths. In another study, when strength of spiritual beliefs and practice was measured, close relatives and friends of someone who died who scored high on spiritual beliefs seemed to resolve their grief more quickly as measured at the 14-month time frame (Walsh, King, Jones, Tookman, & Blizard, 2002). This study, however, may have benefited from following participants longer and also inquiring

about positive outcomes rather than only grief outcomes.

Recently, Folkman (2001) has revised her theory on coping to include positive affect as part of a class of meaning-based coping processes that helps to sustain coping over the long haul. This revision attests to the importance of affect in addition to the previously valued mechanisms of cognition for facilitating meaning-based coping. Hogan and Schmidt (2002) found that the best fit for a model of bereavement showed that bereaved persons first experienced despair, then intrusive thoughts, followed by avoidance of these states which culminated in a search for social support leading to growth. Their model provides evidence for the need to shift coping strategies to more problem-focused coping techniques if one is to make meaning from the loss. During the interviews, participants often discussed the use of escape, avoidance, and guilt. However, as will be discussed below, these strategies were not consistently used, but employed in a fluctuating fashion with more emotion-engaging coping strategies that would reflect a more emotion-focused coping approach employed earlier on. These included going to the cemetery, spending time in the child's room, and smelling the child's clothes.

Parents felt that it was absolutely necessary for them to experience the full depths of grief before they could move forward in their process of meaning-making. As time passed, usually after two or three years, there was a shift to using problem-focused coping strategies more regularly such as joining a support group, reading relevant literature, and making choices that were personally beneficial and not self-punishing.

Growth and Time Since Death.

Participants in the current study found that they realized that they could not continue feeling such negative emotions, that they needed validation, and they needed to start changing their values, priorities, commitments as a testament to their child. This process unfolded gradually over time with parents recognizing the value of sinking into their grief before they could create meaning from their loss. Many parents felt that it took at least four to five years before they felt that their efforts towards meaning were realized more fully.

Murphy, Johnson, Wu et al. (2003) found that 70% of parents who lost a child to a sudden violent death stated that it took 3-4 years to put their child's death into some kind of perspective. While perspective and meaning may not be synonymous, it underscores the understanding that the loss of a child takes many years to work through to some level of self-perceived effective coping. In another study on the same sample, Murphy, Johnson, and Lohan (2003) found that of the 138 bereaved parents, 57% stated that they had found some meaning in their child's death 5 years after the loss. However, time seems to have been inconsistently measured in this study (they lost funding for the time period between 2-5 years post-loss). Despite the lapse, at the two measured times, they found that none of the parents reported finding meaning early on and only 12% found meaning up to 2 years post-loss. Therefore, somewhere in between the 2 and 5 year mark, parents embarked on a journey to find meaning

Other studies have also found that time seems to affect the meaning process and outcome. Lehman et al. (1987) found that 52% of parents who lost a child to a

motor vehicle accident tried to find meaning as measured by a 5-item questionnaire but that 4-7 years after the accident parents still scored high in depression, had higher mortality rates and were less likely to be in their same job. This finding is consistent with reports in the current study whereby parents report that it takes a number of years for the search to begin and that there is no definitive end.

Lehman's study also confirms the current study that found that making meaning and grief are not mutually exclusive experiences. Finally, it suggests that not all parents will be able to find or make meaning from their loss and that despite negative feelings, meaning efforts are still made. Davis et al. (2000) also found that adults whose child or spouse died in a motor vehicle accident or parents whose child died from SIDS do not find meaning one year after the loss, consistent with the theory that the meaning search takes some time to initiate. They found that those who made meaning were better adjusted but that they also continued the meaning search as if there were no specific end point. These results are consistent with this study whereby parents concede that they will continue to create meaning from their child's life and death for the duration of their lives

The current study has described a unique process of meaning-making. Parents initially try to make sense of their child's diagnosis and subsequent illness but make little effort to make sense after the child dies. The parent instead, moves into trying to find meaning which is tied to their existential and spiritual search. Once some reconciliation of this search has been found, parents make meaning and move those beliefs and values into daily actions and commitments. Parents describe that sinking into great depths of grief, being validated by significant others, reconciling

that the child's illness and death cannot make sense but there is some greater unknown reason, were all instrumental in this process of meaning-making. This process will now be discussed in relation to the bereavement models put forward by Neimeyer and by Stroebe and Schut.

Meaning-making Process in relation to Neimeyer's Meaning-Reconstruction Model

The constructivist paradigm is well suited to this study both from a methodological orientation and from a theoretical perspective. Methodologically, the meaning-reconstruction model as described by Neimeyer (2001a) is narrative in nature. Neimeyer states that as meaning-makers we, by necessity, create stories about our lives so that our lives make sense. When an event occurs that does not make sense, that is, the narrative does not fit with our assumptions and values -- then we are faced with the dilemma of how to process that event. Do we assimilate it or accommodate it? In the 21st century, the death of a child in most Western cultures does not make sense; therefore, a parent is faced with an overwhelming challenge of how to cope with their loss. Parents in this study agreed that losing their child seemed inconceivable as Nora described, "Was I prepared? You know, to which I respond, how do you say goodbye to the child? How does a mother say goodbye to their child?" (October, 2003). Nora powerfully captures the intense dissonance between assumptions and her experience. Because 21st century Western culture has little discourse or rhetoric for childhood loss as Neimeyer (2001a) describes, the parent does not have easy access to a culture that can facilitate making sense of the loss. A choice then that the parent has is whether to be an active participant (Neimeyer, 2001b) in their response to the death or a passive

recipient. Neimeyer suggests that as meaning-makers we should be active participants.

Most parents in this study seemed to have made a clear choice at some point in their bereavement that they could not go on in their current state. They decided that the negative feelings of bitterness, resentment, anguish, and anger could not continue to be the dominant emotions. Instead they became active participants in their grief and started making different choices about how to live their lives. For these parents, this choice encompassed the role of parent. They were going to be better people for their child. In this way, parents maintained a relationship with their child.

This choice relates to Neimeyer's (2001a) further assumption of meaning-reconstruction, that of the relational self. Neimeyer states that how we define ourselves or our self-narrative changes over time, situations and across people. Therefore, the pivotal event of losing a child places a parent in new situations and with different people potentially, thus affecting their self-narrative. Parents reported needing to be understood and validated, thus they sought out and welcomed any person who would share stories about their child or who would listen to the parent talk about their child, or just merely sit with them. Parents realized that these individuals were valued supports, and that not all people were willing to listen or to provide emotional support. And as Hogan and Schmidt (2002) discovered, the seeking and receiving of social support was a pivotal point in bereaved persons' growth.

Neimeyer's (2001a) final assumption is evolutionary epistemology. Here the self is under experiment, trying on new identities and behaviours until something feels comfortable. In this study, after parents realized that they could not continue feeling and behaving the way they had been and had reconstructed a more meaningful worldview, parents made efforts to try new things. They were willing to test and trust the world that something positive would emerge from the process. Thus, as Neimeyer (2000) emphasizes, meaning reconstruction is not only about achieving a goal but it is also about the process of making meaning.

As mentioned earlier, one of the challenges of the bereavement literature is that theory and research are not always linked. From Neimeyer's perspective of meaning-reconstruction, the current study substantiates all of the assumptions in Neimeyer's model. Neimeyer's model is helpful in that it describes meaning-related issues but it does not really propose a process. Because The Dual Process Model is the most recent empirical model proposing a process, are there unique features in the meaning-making process that are distinct from the Dual Process Model?

Meaning- making in relation to the Dual Process Model of Bereavement

Strobe and Schut's (1999) Dual Process Model of Bereavement (DPM) is the most current model being empirically and qualitatively explored. Archer (2001) suggests that the DPM provides a broad perspective on grief theory. The model was based on widows and widowers; however, they have encouraged others to explore the fit of their model to other forms of bereavement. Strobe and Schut (2001) state that "what remains to be examined empirically is the process itself of oscillation"

(p. 69). As described earlier, there are several key elements to this model which differentiate it from earlier models that were more phase-based or Freudian-based.

Stroebe and Schut (1999) define two main foci of bereavement which they term orientations. The first orientation is loss-orientation. This orientation most closely resembles the older models of bereavement, namely the focus on the dealing with and processing of some aspect of the loss. Ruminating about the deceased person, yearning, crying, and experiencing the range of emotions all fall under the loss-orientation. The loss-orientation is usually the dominant focus early in bereavement but with time, there is a waxing and waning of the grief-related emotions. Like the emphasis of other models such as Rubin's Two-Track Model (1981, 1999), the theme of this orientation is on the bond, the attachment, and the continuing relationship with the deceased. The second orientation is the restoration-orientation. This orientation represents a more novel aspect to bereavement than previously described in the literature. The restoration-orientation describes the secondary stresses of the loss in two ways. First, there are the sequelae of loss such as loneliness and then secondly, there is the question of how to deal with the sequelae, such as choosing to be with others. Attached to these coping responses are emotions such as discouragement or pride, for example.

The next important feature of this model is the oscillation between confrontation and avoidance of the varying stressors associated with bereavement. This oscillation is a cognitive task whereby the bereaved person engages their grief by engaging in a variety of actions such as going to the cemetery or conversely making efforts to avoid their grief such as by being busy or distracted. Stroebe and

Schut propose that the oscillation will relate to mental and physical health outcomes. Thus, they postulate that it may ultimately be healthier for the bereaved person to take time away from their grief.

M. Stroebe and Schut (2001a) have argued it is imperative that first, the term “meaning” needs to be empirically defined. They suggest that what is missing in the current efforts towards a meaning definition is a focus on the cognitive processing that goes on in bereavement. Stroebe and Schut equate cognitions to meanings. I would suggest that this definition is somewhat limited and would follow Folkman’s (2001) recommendation to include affect as also representative of meaning. Neimeyer (1998) also highlights the value of feelings as independent sources of information. For example, Carrie talks about the depression that she felt, but at some point she felt motivated in her depression to get out of it.

You try not to deal with the pain, it’s not a fun thing and you don’t wanna (chuckles) you don’t wanna have to deal with it, right. It’s just, yeah. I’m thankful that I have, had depression, right now I say that I’m thankful for it. I think it’s, depression is a good thing if it’s, I mean, I wasn’t I guess clinically depressed in that sense? So, if you have it it’s a way of, you’re either going to work your way up or you’re going to stay where you are or go down, you go one way or the other, and I certainly wanted to, I kept saying to myself ‘I’m so lucky for the life I have, I’m so lucky for the children I have. I knew that that was the way it is, I just couldn’t feel that way. (November, 2003)

Folkman suggests that positive appraisals which she equates to meaning-based process, lead to positive states. And as seen above, a negative state such as

depression can be motivating to search for and create a positive state so as to provide some relief. Finally, a positive psychological state can in turn, lead back to appraisal and coping, thus maintaining a positive coping effort. Therefore, affect and cognition play interdependent and crucial roles in meaning-making efforts.

The DPM has recognized the importance of meaning as defined by benefit or growth; but there is no current research which investigates the model in relation to the process of meaning-making in bereavement. Therefore, can this model of bereavement that was developed on widows and widowers, address the meaning-making process of bereaved parents? The following description will compare the parental descriptions of their process with the DPM.

The First Year

As the DPM suggests, the first period is filled with loss-orientation themes. In this early phase, the model suggests an approach-avoidance oscillation between experiencing and not experiencing negative emotions. In this study, the parents reported feeling great pain and anguish.

I think there was an intense pain. Um, and it was just a hole – it was very intense and it was painful, but it was about longing for her and wanting her back and you know, I'd go days – that's all I could think about was getting her back. You know, I was ready to throw in the towel um you know, and thinking thoughts like that and thinking going to the cemetery and you know, doing what I needed to do just to get closer to her. (Brenda, February, 2004)

Brenda captured the intense pain and the need to stay connected to her child which for her, as with a few of the other parents, meant contemplating suicide. The

oscillation that parents reported during the first year were experienced sometimes willfully and sometimes surprisingly. Carrie described the roller-coaster of coasting along and then emotionally plummeting, “And that’s how, more less how I coped. And I kept thinking, I think we all do this, I think, ‘Okay, I’m doing pretty good’. Good, I’m doing pretty good. Like, we’re so happy when you were doing good but it just never lasted. You just kept going back down. You just didn’t know what was going to trigger it?” (November, 2003).

Karen described how she would try to avoid her negative emotions but then purposely engage them,

It’s funny how – it naturally happens. I would, for the most part, probably try not to go there? So in other words, I would try to avoid it. Um, because who wants to feel lousy? But then you get to the point where, (clears throat) it’s like blowing up a tire, you just, it’s going to blow if you keep doing it. I mean, you just keep putting air in, it’s going to blow. So then you just have these, what I call, these little melt downs. And then you’re forced to just be with it... I’d pull out photo albums of Kara quite ill and I’d look at videotapes of Kara and just, that makes you really sob and you know, it’s so hard to think that I lived through that! (February, 2004)

During this early time, parents rarely tried to make sense as Davis et al. (1998) distinguishes but instead began to focus on the spiritual and existential aspect of meaning. Making sense suggests that it fits with our assumptions and beliefs about the world. Trying to make sense of their child’s death proved to be an

overwhelming, emotional, and ultimately pointless task for parents in the current study. This result is consistent with Murphy, Johnson, and Lohan's (2003) study whereby parents initially sought to make sense, and when that proved to be unsatisfactory, parents ultimately initiated a search for meaning as benefit or growth.

It's not like losing a parent. You know, they're eventually going to go and they're older so, even growing up, you know. Eventually your parents are going to go and supposedly they're going to go first before you are. So this, this just defies everything. It's not the norm. And it shouldn't happen.

(Annette, February, 2004)

And as Nora pointed out: "It's meaningless to me because the only thing that I have room for right now is my grief" (October, 2003). Therefore, during this early time, parents were focused on their emotions which left no room for positive reappraising. Parents felt that the intense emotional engagement and expression was an important part of their process of meaning-making even though each parent engaged their pain differently and at different times. And in terms of avoidance of grief found in the loss-orientation, Nora points out the relief of avoidance:

I couldn't have avoided thinking about it, no. Yeah, that technique works well? Um, professionals are always terrified – 'denial, oh that person's in denial'. You know what? I think denial's great! It is the most wonderful coping tool out there. If you can deny this for a while, go right ahead!

The only problem is it'll come up and slap you at some point. (October, 2003)

Most parents also reported being very sensitive to ‘signs’ or perceived messages in the environment from their child. They interpreted these messages as a positive sign that their child was alright: “Although, and I’ve been told that this is a normal part of grief, I don’t know, but I, it took about 6 or 8 months, but I had a dream, and in the dream, Candace told me she was fine. ‘I’m okay mom’. She was on the subway in Toronto, and I was on it. I got on there and I said to her “I’ve been looking all over for you” and she goes “I’m okay mom. I’m alright.” (talking so softly) (Joan, October, 2003).

Therefore, the negative emotions and efforts to maintain the relationship are consistent with Gamino, Hogan, and Sewell’s (2002) qualitative study of bereaved persons. In their content analysis of written responses to the question “what does the death of your loved one mean to you?”, feeling the absence which included yearning, void, and lost dreams were the most prominent experiences at the 8-month median time frame.

In terms of restoration-orientation themes, the primary focus that emerged in this study was on the parents’ personal definition of parent. Particularly for parents who lost their only child, parents struggled with defining themselves as parent, or identifying how many children they have/had.

Um, it’s inter- that’s a really good question. I still struggle with when people like, people say to me ‘How many kids do you have’? And it’s interesting, often when I pick someone that I tell, and it’s not very often. Usually I’ll just say two and in my mind I’ll say three. They’ll have, they’re either a nurse or they have lost a child, or there’s something there

that I know, I just sense, I'm not sure why. But more often than not, I just say I have two kids and in my head I go 'three'. (Patricia, February, 2004)

Contrary to spousal loss, parents needed less to learn the tasks, duties, and chores of the deceased person as the restoration-orientation describes. However, particularly for the parents whose child had been ill most of his/her life, the parent was acutely aware of losing the role of caregiver. Therefore, the unique facets to these bereaved parents in restoration-orientation centred more on identity issues which is consistent with Milo's (2001) study of mothers who lost a disabled child. Additionally, the participants' descriptions of changes in their personal identities are consistent with Nolen-Hoeksema and Davis' (2002) view of growth. They define growth and transformation as "a fundamental shifting of the life goals and purposes that significantly influence one's sense of identity" (p. 599).

The restoration-orientation also addresses relationships. Social support for the parents was felt to be an ongoing struggle. There seemed to be oscillation within this particular facet whereby parents wanted people around but also wanted to be alone.

I: "How long did it take before the phone stopped ringing and the doorbell stopped ringing?"

P: A month, 6 weeks. You know, other people's lives go on! They really, they really, they 'Hey! I was there with you through the whole thing. It's over, it's done with. I don't want to hear about this anymore. You know, because guess what, there's a party tomorrow night, want to come? Like what is there

to celebrate, what is there to be happy about? (softly speaking) My life is a mess! (Nora, October, 2003)

Therefore, in the first year the focus is on grief work- feeling and avoiding the intense pain and recurrently seeking stimuli to activate the pain. Parents were filled with memories and thoughts of their child and felt that they had little choice in the timing and intensity of their feelings. They did not want to break bonds with their child and found ways to feel closer to their child such as spending time in their room or being highly attuned to environmental cues. This receptivity was linked to their questioning of their beliefs, faith, and spirituality. However, parents reported needing some respite from the pain. In terms of restoration-orientation, parents struggled with identity issues and relationships.

Overall, there does not seem to be much divergence from the DPM, suggesting that parents who go on to search for meaning may not be readily identifiable in the first year. However, Attig's (2001) distinction between finding and making meaning is an important one to consider. The DPM assumes that when a parent is not actively engaged in the restoration orientation which would be related to meaning-making, they are probably focused on grief related issues found in the loss-orientation. Attig's distinction of finding meaning raises the value of receptivity which is an important one as emphasized by the parents and may relate to another aspect of the loss-orientation to work through.

The Second Year

As stated earlier, parents were surprised to discover that the second year felt worse. However, despite reporting that the feelings worsened, parents also reported that they felt more energy. This energy could be directed into new relationships, actions, cognitions, and values. It seems that it is at this period that parents, who go on to find meaning, seem to forge a different path. Therefore, the overall oscillation between the two orientations focused on the continuation of grief with a new attention to positive feelings, appraisals and goals.

Parents seemed to have hit a “T-intersection” or “cross-roads”. Folkman (1997) suggests that this cross-road may be the culmination of negative affect which cries for relief. It is here that parents made the decision to search for meaning from their loss. Parents seemed to have reconciled many of their existential and spiritual beliefs enough that they wanted to translate these beliefs and values into action. The DPM does not state this point so clearly. Instead, the model describes an oscillation. The parents’ descriptions suggest that there may be a suspension or hovering around issues as well as critical points of departure. Parents in this group largely felt that there was a distinct turning point:

And that’s kind of where I wake up one morning and get the ‘ah hah!’ crossroads thing happened. I call it the crossroads and it’s my own word, but to me it really was. It was reaching an intersection and saying you’re going left, you’re going right. Which one are you going to take? Cause you can’t continue to go forward, that’s not an option, it’s a T-intersection. And saying...and, part of that was coming with the understanding of legacy, which

it took me years to discover the word legacy. To be able to label it like that. I used to call it gifts. (Nora, October, 2003)

Nora clearly describes a point in time where a decision had to be made. These parents seemed to have chosen to search for meaning in the life and death of their children. Nora also addresses the element of time. At this point in the process the parents who have decided to search for meaning, do not know where it will take them. It is not an outcome, but the beginning of a journey that most admit will last their lifetime. Therefore, parents have regained some trust and/or faith in the world or in their spiritual beliefs. They are becoming active participants in Neimeyer's words and they have started shifting to finding some benefit (Janoff-Bulman & Frantz, 1997). This is especially critical in that parents felt betrayed by the world and by "God".

Another important finding in this study is the evolution in the parents' perception of themselves. Parents felt judged and inadequate during the illness; they felt tremendous guilt for not having done enough for a period after the death. Over time, parents reported having much more respect and compassion for themselves and consequently, view themselves much more positively. The DPM does not address the relationship to the self. While it does address identity, it seems to be related more to identity in relation to others. Parents describe more how their personal identity has changed such that they feel an enhanced self-respect and self-esteem.

In terms of social support, parents have realized that many of their previous friendships are no longer satisfying: "Um, I mean, my friends tried their best – I

didn't make it very easy for them. Um, being bereaved rewrites your address book. Totally.” (Nora, October, 2003). However, with this renewed energy, parents needed to begin to reinvest in the external world, but they were faced with the reality that many of their supports, friends, and family members did not want to continue talking about the parent's child or support the parent's ups and downs. Consequently, most parents in this study turned to a support group. Interestingly, while most parents found this experience to be a pivotal one in their bereavement, parents did not report maintaining life-long friendships out of the support group. Instead, the group seemed to act as a vehicle for parents' validation and normalization of experience and feelings. Once this had occurred, parents felt that they could engage in new relationships or reinvest in chosen old relationships. Hogan and Schmidt (2002) confirm that this validating support is the pivotal shift for parents in their study who went on to create meaning.

Regarding the bond with the child described in the loss-orientation, parents still wished to maintain a bond with their child and still looked for 'signs' from their child: “And messages. I love getting messages from Kara. I get them all the time!” (Karen, February, 2004). The decision to find meaning in their child's life and death may be understood as a way to maintain a positive relationship with the child. This assures the parent that the child will never be forgotten. This choice to maintain a relationship with the child is in direct contrast to the Freud's original griefwork hypothesis which recommended a relinquishing of the bond.

Therefore, the oscillation that seems to occur in the second year in the loss-orientation centres around approaching and avoiding the grief feelings, initiating

ways of maintaining the parent-child relationship and being receptive to signs or messages so as to sustain the relationship. Finally, the parent has decided, in response to the overwhelming negative feelings, they cannot continue in that manner and thus, decide to create a more meaningful life through the search for meaning in their child's death. The restoration-orientation oscillation is found in the negotiation of new relationships, engaging in the external world, and struggling to define themselves as a parent.

This study suggests that the DPM may be limited in its understanding of the distinct aspects of finding and making meaning. Finding meaning may relate more to the loss-orientation while making meaning seems to fall under the restoration-orientation. As well, the DPM does not identify the importance of the changing personal identity of the parent.

2 Years and Beyond

As mentioned previously, one of the limitations of bereavement research has been that outcomes have rarely been documented beyond two years. These parents have confirmed that meaning-making is just beginning at this point. Parents felt that once they had decided that they were going to create meaning from their child's death, parents made this a point of departure for almost all major decisions. Parents found that their grief emotions decreased in frequency and in intensity, though there were times when they felt great pain. Not feeling pain was met with some oscillatory reaction. While parents appreciated being able to re-engage in the world, they initially felt remorse and guilt when they first experienced a lessening of painful emotions.

And I would say up until 5 years it was, pretty much like the major part of my life. Like he was always sitting on my shoulder. Like whatever I was feeling or doing he was there somehow. And somehow around the 5 year point, I suddenly realized that ‘Wow’! I went the whole day without thinking about him. And that was really sad actually for me at first. That was a hard thing. And now I just realize I’ve gone to the next phase or whatever, I guess.

(Patricia, February, 2004)

It is evident that Patricia is not altogether convinced that it is a good thing she went a whole day without thinking about her child. Parents’ emotional lives are forever changed by the death of their child. Despite a “background noise” of sadness, parents have struggled to engage in meaningful acts that somehow provide a counterweight to the sadness. June Callwood captured these sentiments in an interview with Paula Todd on Studio Two (Grant, Person 2 Person, October 26, 2004). When Ms. Callwood reflected on her terminal cancer, she said she embraced death because “I’ve been sad too long”. Her son was killed by a drunk driver more than a decade ago. When Ms. Callwood was asked what she wanted to be remembered for, she replied, “that I tried”. These two statements seem to succinctly capture parents who have created meaning from their loss. On the one hand, they acknowledge an overarching emotional change towards the negative, but despite it, they have tried to create meaning from their pain.

Over time, and it would seem a number of years for bereaved parents, the relationship the parent has maintained with the child transforms. The omnipresence of the child found in the earlier period of time has lessened. The

relationship with the child is a negotiation between child-as-guide-to-parent and parent-as-protector-to-child. This description of the parent-child relationship is more complex than described in other models such as Rubin's Two-Track Model (1981) who most fully explores the relationship over time. While Rubin maintains a psychodynamic perspective regarding attachment to the deceased, he does not describe how it may inform a parent's choices, actions, and values.

The restoration-orientation has assumed the dominant focus now with a concentration on positive meaning reconstruction. The revised trust and faith initiated earlier has opened parents up to new relationships and experiences. Sophia describes her recent experience six years after her child died:

Well, I'm just, it's just, I'm just peaking right now. I feel like I've just done a big, big, big jump and I'm finding myself on a new island, and I've landed? And I'm not sure what's on this island, but I'm willing to discover it 'cause it's going to be a beautiful island. And how all of it will evolve, where I'll..., I have no idea (whispering) but it's beautiful. It's a nice place to be. It's solid.(softly) (July, 2003)

Sophia articulates an awareness of change and an acknowledgement that it is a never-ending process of growth. Relationships have also changed over the years such that parents make decisions about what kind of people they will keep in their lives. It is no longer about status but instead about a shared value of honesty, integrity, respect, and caring as Sophia said, "I guess I've been reflecting last week and...recognizing that I need people, and nice people, not just anyone, nice people

and who respect me and who I respect, and that are not out there just for themselves.” (July, 2003).

Finally, parents changed their energy focus into socially-driven activities. The DPM does not discuss the actions but instead mentions that the goals change. While the goals are an important beginning, the goals made manifest in daily activities demonstrate the lived quality of a meaningful life as Nora described: “I think that my philosophy of, of the purpose of life in a nutshell would be to leave the world in a better place than we found it. Whereas before it might have been he with the most toys wins when they die?” (October, 2003).

Parents have experienced profoundly the vulnerability of life and it is in this realization that parents have re-engaged their life by making new choices that reflect this realization. Armour (2003) interviewed family members of individuals who were murdered. In a qualitative study, she found that the changes in values and “what really mattered” needed to be made manifest in action. In the current study, parents exercise control where they can and know that the outcome may not be what they intended. For that reason, they experience gratitude more readily and easily at the smallest of things.

Finally, in terms of meaning outcomes, parents’ relationship to themselves changed. Parents said that they felt an increase in self esteem and self acceptance:

Sense of self has changed. Yeah, well again, the depression did that for me, because um, I am moving toward being the best that I can be now. And I wasn’t doing that before. I was being the best for everybody else maybe? And

now I know it's important to make myself whole and then I can give. (Carrie, November, 2003)

And finally, Annette described the ways in which she actively tried to improve her self esteem:

I didn't know what to do with myself... I can do things. Things that will make me feel good. Start picking up hobbies and things that I enjoy doing to make me feel more alive I guess? ...for satisfaction, to give myself some worth? Some self-worth? Where, you know, I didn't feel like it before, when you're so down and when you start having some half decent days, obviously... I can do this, and I need to do this to survive. To give me a reason to get up in the morning. Have something to look forward to you know. Some self sense of accomplishment, even if it's a minor little thing. (February, 2004)

The years that follow the decision to create meaning from their loss, parents feel their grief less intensely and less frequently. They have reframed some of their experiences positively and have defined some of the painful events as necessary to their growth. Parents are involved in social causes that most often benefit other children, and they describe themselves as generally more sensitive and responsive to others. Parents do not feel that there is an endpoint but that their growth will last their lifetime: "Oh yeah, oh yeah, oh yeah, it is a lifetime. Definitely. I know that I'm the right track because my base is solid now. And, I'm ready for a change, I'm so, so, ready." (Sophia, July, 2003)

The Dual Process Model has provided a useful frame from which to explore the process of coping with loss. However, the parents in this study have highlighted some areas that are worthy of exploring further which are not made explicit in the DPM. Namely, parents describe a process of finding meaning which relates to a receptivity to the environment as well as to a questioning of existential and spiritual meaning. Secondly, they have described the importance of re-defining their relationship with their child as an important part of their meaning-making which is linked to their existential and spiritual questioning. Parents also reported a distinct turning point which was precipitated by intense negative feelings but countered by a certain return of energy. Parents also feel that their answers to existential questions helped them move forward into engaging in positively meaningful acts and commitments. Finally, parents predict that they will be invested in this process for the rest of their lives.

GENERAL DISCUSSION, CONCLUSIONS, & RECOMMENDATIONS

This study has contributed to the growing body of research in bereavement by describing the process of meaning-making in bereaved parents. Most researchers in the past have centred their research on negative outcomes to loss while only a few researchers have focused on meaning outcomes. Further few have tried to describe the process of meaning-making empirically. Neimeyer's Meaning-Reconstruction Model provides an accurate description for the themes of change as a bereaved parent negotiates his/her narrative. The Dual Process Model of Coping with Loss theoretically postulated a process of meaning; however, the empirical research was

lacking in terms of validating the model. This study did not begin with the intent to validate the DPM; however, it would appear that many aspects of their model are born out in the interviews of bereaved parents. However, this study identifies a number of areas for further inquiry.

Patton (2002) suggests that when appropriate, the use of a metaphor may graphically capture an experience studied qualitatively. As I reflected on the stories of the parents, the image of a kaleidoscope emerged. The eyepiece or the lens is made of the more stable aspects of ourselves that will always colour our perceptions, such as personality or optimism/pessimism. This kaleidoscope has many rotating wheels that can affect the image of broken shards seen at the other end. Events in life will shake the kaleidoscope and affect the image at the other end. Shaken up and without efforts at adjustment, these shards seen through the lens are painful and unsettling. So we turn these wheels in an effort to create a new image that gives us satisfaction, pleasure, and meaning. These wheels can be adjustments of coping, emotions, social support, values among many others. Sometimes we may only be able to move one of the wheels while other times, we may feel more able to move multiple wheels simultaneously. In a kaleidoscope, we will never recreate the old image, but through constant adjustments, we make efforts at creating new images.

From the descriptions of parents, there are a few points that are worthy of future research. Future research may wish to incorporate the effect of the illness experience on the bereavement experience, on distinguishing among the various aspects of, and evolution of meaning, and finally, on some of the

experiential/transformational (Kolb, 1984; Mezirow, 1981) learning literature which regards the experiences, actions, and behaviours as intrinsic to change.

Additionally, in relation to meaning outcomes, parents felt that they had greater self-worth, self-esteem, and self-acceptance. This addition brings up the intrapersonal aspect to meaning in addition to the more commonly researched interpersonal dimension.

This study described the bereavement and meaning-making experience of bereaved parents. The sample itself was a purposeful sample in that parents were bereaved of a child under the age of 25 who died of an illness that lasted a minimum of 6 months. While this group of bereaved individuals has not been studied to any great extent, it is unclear whether their meaning-making process is similar to a person whose loss was more normative such as losing a parent or older spouse, or for those whose loss was from a sudden or violent death. Also, the sample was largely derived from a support group network and most of these parents felt that the support group was a pivotal point in their bereavement process. Further work on non-support group bereaved individuals would help to illuminate the process. This study also was retrospective and thus, is not necessarily historically accurate. Nevertheless, it is the construction of perceptions that help shape the parents' present and ongoing meaning. It is also unlikely that a prospective study could be done in this manner over as many years. And finally, the title of the research included the words "meaning-making", thus, chances are, one who had not self-identified him or herself as finding or searching for meaning probably did not

choose to participate. Again, triangulation of participants is affected here in that there were no other 'types' of participants.

The death of a child seems to have provided the reason for parents to make significant changes in their lives. The death was the catalyst but the ongoing efforts and choices of the parents are what define the process of meaning-making. Additionally, parents have confirmed that much of the outcome literature on the negative sequelae of grief may be true, but for many bereaved parents, there is more to their bereavement. Negative outcomes are not the only experiences. Many parents try to counter those feelings with a positive change in values, commitments, acts, and relationships which in turn provide positive emotional experiences. These changes are consistent with Baumeister and Vohs' (2002) four needs for meaning. They state that a person who satisfies these needs will likely describe themselves as living a meaningful life. The four needs are: need for purpose, the need for values, the need for self efficacy, and the need for self worth. The various quotes above articulate the parents' search for and ultimately satisfaction of, these needs. Clearly more research is needed in this area so that those bereaved individuals who are struggling in their search may find some help in the stories of others.

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Appendix A

Correlation Matrix of Quantitative Results

Inter-correlation Matrix of Demographic and Quantitative Variables (N = 16)

	Age at Testing	Education Level	Growth	Grief (no growth)	Neuroticism	Time Since Death	Social Support Satisfaction *
Age at Testing	.26		-.02	-.21	.07	.57**	.15
Education Level			.37	.24	-.11	.30	-.08
Growth †				-.31	-.36	.52*	.20
Grief ‡ (no growth)					.68*	-.01	-.47
Neuroticism §						.21	-.11
Time Since Death							.04

* $p < .05$. ** $p < .025$

* Sarason, I. G., Levine, H. M., Basham, R. B., & Sarason, B. R. (1983). Assessing social support: The Social Support Questionnaire. *Journal of Personality and Social Psychology*, 44, 127-139. (See appendix I for the questionnaire)

† Hogan, N., Greenfield, D. B., & Schmidt, L. A. (2001). Development and validation of the Hogan Grief Reaction Checklist. *Death Studies*, 25, 1-32. (See Appendix J for the questionnaire)

‡ Hogan, N., Greenfield, D. B., & Schmidt, L. A. (2001). Development and validation of the Hogan Grief Reaction Checklist. *Death Studies*, 25, 1-32. (See Appendix J for the questionnaire)

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Due to the small sample, these results are viewed as descriptive only. Nevertheless, the significant relationships between grief and neuroticism and growth with time suggest that these are robust measures and are worth pursuing with a larger sample.

Appendix B

Notice Placed in Newsletters

You are invited to take part in a research study. This project is a Doctoral thesis at Concordia University in Montreal. This study is investigating the bereavement process of parents who have experienced the death of a child through illness. Previous research documenting bereavement experience has not focused on the bereaved parent. Therefore, I wish to fill this gap in the research with the hopes that health care professionals, and family and friends can better help and understand the grief experienced by parents.

You will be asked to fill out 5 questionnaires which will take approximately one hour. You can fill out the questionnaires through my website at psychology.concordia.ca/fac/pushkar/pbereave.html

For more information please refer to the website. You can contact me at griefpro@alcor.concordia.ca

Appendix C

Questionnaire #1 including Demographic Information

DEMOGRAPHIC AND INFORMATION SHEET

1. Relationship (Please circle): Mother Father

2. Your year of birth

3. City of residence:

4. Marital status (Please circle): Married Common-law Separated
Divorced Single

5. Highest level of education (Please circle): High school College
University Post-graduate University

6. Occupation:

7. Number and ages of children

8. Child's Name and date of birth (mm/dd/yy)

9. Child's date of death (mm/dd/yy)

10. Child's type of illness

11a. Did your child experience a remission? If so, what were the dates? _____

11b. Did your child experience a relapse? If so, what were the dates? _____

For the following questions, please feel free write on the back or add paper if you require more space.

12. Please describe in general terms (not medical) your child's medical treatment. Describe the length of treatment, the frequency of treatment, the distance travelled to receive treatment and your involvement in treatment and treatment decisions.

13. Please describe any changes or disruptions in your family as a result of attending to your child's medical treatment. Refer to your other children (if any), your extended family, friends, and school.

14. Briefly describe the ways that your family, friends, clergy, and people responded to you and your grief reaction. Please describe if this was emotional, psychological, practical, spiritual etc. How were these people helpful and not helpful to you?

15. Briefly describe the reactions and responses that family, friends, clergy and others made to the death of your child immediately after your child died; at 6 months; 1 year; more than one year. Please describe if this was emotional, psychological, practical, spiritual etc.

16. Please describe what you needed emotionally, psychologically, spiritually, and practically, immediately after your child died; 6 months later; 1 year later, more than 1 year later. Please describe ways in which these needs were met or not met.

17. Have you changed as a result of the death of your child? In what ways?

Letter of Introduction

INFORMATION LETTER

Research Study: Meaning-making in Bereaved Parents: Process and Outcome

You are invited to take part in a research study. This project is the Doctoral thesis research for Suzanne Lister at Concordia University in Montreal, Quebec. This study is investigating the bereavement process of parents who have lost a child to an illness. Previous research documenting the bereavement experience has not focused on the bereaved parent. Therefore, I wish to fill this gap in the research with the hopes that health care professionals, and friends and family can better help and understand the bereavement experienced by bereaved parents.

You are asked to fill out 5 questionnaires. This will take approximately 1 hour. If both parents fill out the questionnaires, please do not consult one another about your responses or ask for feedback. Your personal response is most important. The information gathered here will be added to other information gathered for this study. Specifically, some parents will be interviewed about their bereavement. If you wish to be interviewed, and you live in Ontario or in the Montreal area (and speak English), please fill out the appropriate area and the researcher will notify you to set up an interview date.

This information will be used primarily for the primary researcher's thesis. Subsequent to completion of her doctoral studies, the data may be used for future publications. All information will be kept private and no identifying features will be used in any publication.

The information will be kept for at least 5 years after the study is done. The information will be kept in a locked filing cabinet. Your name and any other identifying information will never be used in any presentations or publications of the study results.

No harm should come to you for answering these questionnaires. However, you may experience some emotional responses as some questions ask you specifically about your bereavement experiences. If you become upset, please talk to a good friend, your doctor, or another support person who can help you. If you require further support information, you can contact the primary researcher via e-mail. She will not keep a copy of your name, telephone number, or any details of the message.

Thank you. If you have any questions about this study, please contact the Doctoral student or her supervisor. If you have any questions about your rights as a research participant, please contact Michelle Hoffman in the Office of Research

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Appendix E

Consent Form

CONSENT FORM TO PARTICIPATE IN RESEARCH

This is to state that I agree to participate in a program of research being conducted by Suzanne Lister, *Meaning-making in Bereaved Parents: Process and Outcome* as part of her research into parental bereavement under the supervision of Dr. Dolores Pushkar of the Department of Psychology at Concordia University.

PURPOSE

I have been informed that the purpose of the research is to investigate the parents' experience of bereavement after the loss of their child. The aim of the research is to provide a description of the parents' process of their bereavement experience.

PROCEDURE

I understand that I will fill out 5 questionnaires. I also may be part of a tape recorded interview. This interview will be transcribed word-for-word. If I agree to participate in an interview, I will notify the researcher who may contact me to set up an interview date. I understand that the researcher will conduct the interview in my home if that is most convenient. This interview will last approximately 1 ½ hours. During this interview, I will be asked to describe my experiences related to my grief since my child died. I understand that questions asked may elicit some grief reactions. If I am distressed or uncomfortable with any questions or with the interview, I may terminate it immediately. I also understand that my name and any identifying circumstances will be omitted so that I remain anonymous to all but the researcher. I understand that a code will be used for all of my information and only the researcher and possibly, research assistant will have access to this information. All information will be kept in a locked cabinet where only the researcher has access.

CONDITIONS OF PARTICIPATION

I understand that I am free to withdraw my consent and discontinue my participation at any time without negative consequences.

I understand that my participation in this study is voluntary and there is no financial reimbursement.

CONFIDENTIALITY

I understand that the researcher will know my name but will not disclose my identity to others or in publication.

I understand that the data from this study may be published.

I understand the purpose of this study and know that there is no hidden motive of which I have not been informed.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS AGREEMENT. I FREELY CONSENT AND AGREE TO PARTICIPATE IN THIS STUDY.

Name (please print) _____

Signature _____

Witness Signature _____

Date _____

I WISH TO PARTICIPATE IN THE INTERVIEW. Please contact me at the following (identify phone number or e-mail address)

Appendix F

Interview Consent Form

INTERVIEW CONSENT FORM

Meaning-making in Bereaved Parents: Process and Outcome

This is to state that I agree to participate in a program of research being conducted by Suzanne Lister, *Meaning-making in bereaved parents: Process and outcome*, as part of her research into parental bereavement under the supervision of Dr. Dolores Pushkar of the Department of Psychology at Concordia University.

PURPOSE

I have been informed that the purpose of the research is to investigate the parents' experience of bereavement after the loss of their child. The aim of the research is to provide a description of the parents' process of their bereavement experience.

PROCEDURE

I understand that I will be interviewed by the researcher regarding the loss of my child. During this interview, I will be asked to describe my experiences related to my grief since my child died. This interview will last approximately 1 ½ hours. I understand that questions asked may elicit some grief reactions. If I am distressed or uncomfortable with any questions or with the interview, I may terminate it immediately. I also understand that the interview will be transcribed word-for-word and that quotes may be used in subsequent publications. I also understand that my name and any identifying circumstances will be omitted so that I remain anonymous to all but the researcher. I understand that a code will be used for all of my information and only the researcher and possibly, research assistant will have access to this information. All information will be kept in a locked cabinet where only the researcher has access.

CONDITIONS OF PARTICIPATION

I understand that I am free to withdraw my consent and discontinue my participation at any time without negative consequences.

I understand that my participation in this study is voluntary and there is no financial reimbursement.

CONFIDENTIALITY

I understand that the researcher will know my name but will not disclose my identity to others or in publication.

I understand that the word-for-word data from this study may be published.

I understand the purpose of this study and know that there is no hidden motive of which I have not been informed.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS AGREEMENT. I FREELY CONSENT AND AGREE TO PARTICIPATE.

Name (Please print): _____

Signature: _____

Date: _____

Researcher's Signature: _____

Appendix G

Interview Guide

Interview Framework:

General Review of Consent Procedures

To begin, I would like to thank you for agreeing to be interviewed. The interviews take about an hour and a half, but may vary from person to person.

Before we begin, I would like to ask for your consent to be interviewed. This is part of the ethics procedures that researchers at the university follow and would require you signing some forms. There are a number of things related to consent. The first thing I am asking you to agree to is your participation in the study. What this involves specifically is agreeing to be interviewed today. As well, I may want to chat with you a second time to go over what you said today, in the event that I may need clarification or more elaboration on something.

My general practice is to tape the interviews. I do this for two reasons. First, the “data” in the kind of research that I do are the actual words that people speak. I want to make sure that when I am working with the data that I have *your* words, rather than *my* interpretation of your words. Second, while I keep notes as we go along (just in case there are some technical glitches), generally what I do is transcribe, word for word, what is said on the tape so that nothing is missed. Just taking notes would not allow me to get down everything that you say.

There are some ethical procedures that I want to tell you about regarding who sees the data and where it is stored. The only people who would actually see the data are myself, my thesis advisors and a transcriber. Generally, though, I prefer to do my own transcription. The tapes and records are kept in a locked file cabinet and I am the only one who has access to it. All of this information will be destroyed once I no longer need the data.

The names of individuals who participate in the study are not used. I have a coding system that I use so that I know who provided the information, but it is that code, rather than any names, that appears on any of the written transcriptions.

As we go through the interview, there may be questions that you would rather not answer. In this case, please feel free to “pass” on that question. I also want you to know that you are free to stop participating in the study or this interview at any time.

The second item for your consent is the use of your quotations in any reports, articles, or the final thesis itself. Again, it is your words that tell the story and in

the kind of research that I do, the use of quotations is very important. Your identity would be kept anonymous so that no one would know who made the comment.

You received a letter that outlines these various points and provides you with the name and phone number of my thesis advisor in the event that you would like to contact her for some reason. The phone number of the Office of Research Ethics at the university is also included. If you require another copy, I have that letter for you.

Do you have any questions that you would like to ask me about any of this?

If not, would you be willing to sign the consent form: that allows me to use quotations from the interview and to contact you again if I require any clarification? (If so, consent forms are signed at this point).

Introduction to the Interview Format

I have a number of topics that I am interested in exploring in relation to parental bereavement. I am interested in your understanding of your own bereavement experience since the loss of your child. Thus, I will at times, specify certain time periods, for example, 1-year anniversary etc.

The general topics that I am interested in learning more about are: your experience just prior to your child's death, and your experience since that time. I am interested in people who were or were not helpful and why, experiences and events that were particularly meaningful for you, your support network over time, and any outcomes you may feel have come about as a result of your loss. While I have some questions to guide us along in the interview process, I am interested in hearing about anything else that you think would be useful to my understanding. I hope that we can use this time as an opportunity for a dialogue, and do not feel restricted by a question and answer type of format.

Finally, if at any time you feel upset or distressed, please let me know and we can pause or terminate the interview.

Would you like to begin now?

Is it okay if I turn on the tape recorder?

Interview Questions*

Because I am interested in your process of bereavement, I will be framing my questions for specific time intervals.

Prior to your child's death

1.1. Can you tell me about your child? What was s/he like?

1.2. What was your experience like during your child's illness?

Probe if necessary: How did your life change- work, family life, support group?

1.3. As you look back on how you coped with your child's illness, what did you find helped you cope?

Did you think that you had these resources within you prior to your child's illness?

1.4. Prior to your child's illness, did you spend much time thinking about the meaning of life? Has this changed since your child died? If so, how?

1.5. Some people have certain assumptions or beliefs about the world such as the world is fair, or people are good etc. When a child dies, sometimes people feel that their beliefs in the world, in their religion, etc. have been shaken. Did you have any assumptions or beliefs that were challenged? If yes, how did you handle dealing with those conflicting beliefs and experience?

* Note: This guide was used as a framework. The wording and order of the actual interviews were more open and responsive to the individual participants.

Immediate Months after Death

2.6 Can you describe how you felt in the days and weeks immediately following your child's death?

2.7 **What** helped you get through those first few weeks?

2.8 **Who** helped you through those first few weeks? Were there certain family members, friends, clergy, or others who provided you specific support? What and how did they provide support?

2.9 During those first months, were there any things that people said or did that you found unhelpful, hurtful, or insensitive? If you could tell people what is helpful in those early days, what would you suggest?

2.10 During those first few months, were there times when it felt unreal, that your child was still alive?

Were there things that you would do to avoid thinking about your loss or your grief? How did these activities help and not help?

2.11 In the first few months, were there times when you consciously made efforts to feel your pain? How did these activities help? How did this activities not help?

2.12 Were there any ways that you thought about your child that kept him/her in your daily life in that first year?

2.13 Some people say that their beliefs in the world have been changed since the death. If this has happened to you, can you describe what of your beliefs changed during this first year?

1 year anniversary- 2 years

3.14 Did anything change after the one-year anniversary?

Your feelings,

Behaviours,

Your supports?

If so, how did these change?

3.15 As you think about how you coped during the 2nd year, what actions, thoughts, feelings, people were helpful and not helpful?

3.16 During the second year did your relationship with your child evolve? If so, how?

3.17 There are times when people need to avoid their pain and at other times they actively spend time in their pain. Did you need to avoid or engage your grief at times in this 1-2 years after your child died? How did you avoid and engage your grief?

3.18 Some people say that their beliefs in the world have been changed since the death. If this has happened to you, can you describe what beliefs changed during this 2nd year?

After 2 years and general reflections

The following questions relate to the time two years and beyond and also just general reflections.

4.20 If you reflect since the time your child died, how would you describe the way you've been feeling? Can you tell me more about your experiences? Have there been any changes in the way you feel during the x years?

4.21 In looking back over the year (s) have there been times that you have wanted to or have retreated from your family, friends, or support network? If so, were there any positive or negative outcomes to this retreat?

4.22. Generally, who has helped you through your bereavement?
When were they helpful? How were they helpful?

4.23. Can you think of any specific or global changes you have noticed in yourself as the years have passed?

4.24. Can you think of any way(s) in which there have been any positive outcomes or benefit, or growth as a result of the loss of your child?

4.25(If yes to above) Over the past years since your child's death, were there any times where you felt a heightened sense of insight about what meaning, or a positive outcome might be? Can you describe that experience?

4.26. In terms of how you spend your average week now, where do you tend to direct your energy, focus, and actions? Is this different from before your child became ill?

4.27. Are there any other things that you would like to share?

Appendix H

NEO-Five Factor Inventory

(Costa and McCrae, 1992)

Questionnaire #1

There are no “right” or “wrong” answers. Please read each item carefully and circle the answer that corresponds best to your opinion. Answer every item.
Remember, there are no right or wrong answers.

1. I am not a worrier.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

2. I like to have a lot of people around me.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

3. I don't like to waste my time daydreaming.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

4. I try to be courteous to everyone I meet.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

5. I keep my belongings clean and neat.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

6. I often feel inferior to others.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

7. I laugh easily.				
1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree
8. Once I find the right way to do something, I stick to it.				
1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree
9. I often get into arguments with my family and co-workers				
1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree
10. I'm pretty good about pacing myself so as to get things done on time.				
1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree
11. When I'm under a great deal of stress, sometimes I feel like I'm going to pieces.				
1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree
12. I don't consider myself especially "light-hearted".				
1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree
13. I am intrigued by the patterns I find in art and nature.				
1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

14. Some people think I'm selfish and egotistical.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

15. I am not a very methodical person.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

16. I rarely feel lonely or blue.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

17. I really enjoy talking to people.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

18. I believe letting students hear controversial speakers can only confuse and mislead them.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

19. I would rather cooperate with others than compete with them.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

20. I try to perform all the tasks assigned to me conscientiously.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

21. I often feel tense and jittery.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

22. I like to be where the action is.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

23. Poetry has little or no effect on me.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

24. I tend to be cynical and sceptical of others' intentions.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

25. I have a clear set of goals and work toward them in an orderly fashion.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

26. Sometimes I feel completely worthless.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

27. I usually prefer to do things alone.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

28. I often try new and foreign foods.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

29. I believe that most people will take advantage of you if you let them.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

30. I waste a lot of time before settling down to work.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

31. I rarely feel fearful or anxious.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

32. I often feel as if I'm bursting with energy.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

33. I seldom notice the moods or feelings that different environments produce.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

34. Most people I know like me.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

35. I work hard to accomplish my goals.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

36. I often get angry at the way people treat me.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

37. I am a cheerful, high-spirited person.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

38. I believe we should look to our religious authorities for decisions on moral issues.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

39. Some people think of me as cold and calculating.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

40. When I make a commitment, I can always be counted on to follow through.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

41. Too often, when things go wrong, I get discouraged and feel like giving up.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

42. I am not a cheerful optimist.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

43. Sometimes when I am reading poetry or looking at a work of art, I feel a chill or wave of excitement.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

44. I'm hard-headed and tough-minded in my attitudes.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

45. Sometimes I'm not as dependable or reliable as I should be.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

46. I am seldom sad or depressed.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

47. My life is fast-paced.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

48. I have little interest in speculating on the nature of the universe or the human condition.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

49. I generally try to be thoughtful and considerate.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

50. I am a productive person who always gets the job done.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

51. I often feel helpless and want someone else to solve my problems.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

52. I am a very active person.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

53. I have a lot of intellectual curiosity.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

54. If I don't like people, I let them know it.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

55. I never seem to be able to get organized.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

56. At times I have been so ashamed I just wanted to hide.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

57. I would rather go my own way than be a leader of others.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

58. I often enjoy playing with theories or abstract ideas.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

59. If necessary, I am willing to manipulate people to get what I want.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

60. I strive for excellence in everything I do.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

Appendix I

Social Support Questionnaire

(Sarason, Levine, Basham, & Sarason, 1983)

Questionnaire #3

The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first Part, list all the people you know excluding yourself, whom you can count on for help or support in the manner described. Give the relationship to you (e.g. brother, friend, mother, employer). If you state the plural form (eg. Sisters, Friends etc.), please give the number of them. If you have no support for a question, circle the words “no one”. Do not list more than one person next to each of the numbers beneath the question.

For the second part, circle how satisfied you are with the overall support you have. If you have no support for a question, circle the words “no one”, but still rate your level of satisfaction. Do not list more than nine (9) persons per question.

EXAMPLE: Who do you know whom you can trust with information that could get you in trouble?

No one 1) wife____ 4) employer____ 7) _____
 2) son____ 5) daughter____ 8) _____
 3) friend____ 6) _____ 9) _____

How satisfied are you with this?

6	5	4	3	2	1
very	fairly	a little	a little	fairly	very
Satisfied	satisfied	satisfied	dissatisfied	dissatisfied	dissatisfied

1a. Whom can you really count on to listen to you when you need to talk?

No one 1) _____ 4) _____ 7) _____
 2) _____ 5) _____ 8) _____
 3) _____ 6) _____ 9) _____

1b. How satisfied are you with this?

6	5	4	3	2	1
very	fairly	a little	a little	fairly	very
Satisfied	satisfied	satisfied	dissatisfied	dissatisfied	dissatisfied

2a. Whose lives do you feel that you are an important part of?

No one	1) _____	4) _____	7) _____
	2) _____	5) _____	8) _____
	3) _____	6) _____	9) _____

2b. How satisfied are you with this?

6	5	4	3	2	1
very	fairly	a little	a little	fairly	very
Satisfied	satisfied	satisfied	dissatisfied	dissatisfied	dissatisfied

3a. Whom could you really count on to help you out in a crisis situation, even though they would have to go out of their way to do so?

No one	1) _____	4) _____	7) _____
	2) _____	5) _____	8) _____
	3) _____	6) _____	9) _____

3b. How satisfied are you with this?

6	5	4	3	2	1
very	fairly	a little	a little	fairly	very
Satisfied	satisfied	satisfied	dissatisfied	dissatisfied	dissatisfied

4a. Whom can you talk with frankly, without having to watch what you say?

No one	1) _____	4) _____	7) _____
	2) _____	5) _____	8) _____
	3) _____	6) _____	9) _____

4b. How satisfied are you with this?

6	5	4	3	2	1
very	fairly	a little	a little	fairly	very
Satisfied	satisfied	satisfied	dissatisfied	dissatisfied	dissatisfied

5a. Whom can you really count on to be dependable when you need help?

No one 1) _____ 4) _____ 7) _____

 2) _____ 5) _____ 8) _____

 3) _____ 6) _____ 9) _____

5b. How satisfied are you with this?

6	5	4	3	2	1
very	fairly	a little	a little	fairly	very
Satisfied	satisfied	satisfied	dissatisfied	dissatisfied	dissatisfied

6a. Whom can you really count on to give you useful suggestions that help you to avoid making mistakes?

No one 1) _____ 4) _____ 7) _____

 2) _____ 5) _____ 8) _____

 3) _____ 6) _____ 9) _____

6b. How satisfied are you with this?

6	5	4	3	2	1
very	fairly	a little	a little	fairly	very
Satisfied	satisfied	satisfied	dissatisfied	dissatisfied	dissatisfied

7a. Who will comfort you when you need it by holding you in their arms?

No one 1) _____ 4) _____ 7) _____

 2) _____ 5) _____ 8) _____

 3) _____ 6) _____ 9) _____

7b. How satisfied are you with this?

6	5	4	3	2	1
very	fairly	a little	a little	fairly	very
Satisfied	satisfied	satisfied	dissatisfied	dissatisfied	dissatisfied

8a. Whom do you feel would help if a family member very close to you died?

No one	1) _____	4) _____	7) _____
	2) _____	5) _____	8) _____
	3) _____	6) _____	9) _____

8b. How satisfied are you with this?

6	5	4	3	2	1
very	fairly	a little	a little	fairly	very
Satisfied	satisfied	satisfied	dissatisfied	dissatisfied	dissatisfied

Appendix J

Hogan Grief Reaction Checklist

(Hogan, Greenfield, and Schmidt, 2001)

Questionnaire #4

This questionnaire consists of a list of thoughts and feelings that you may have had **since** your child died. Please read each statement carefully, and choose the number that best describes the way you have been feeling during the **past two weeks, including today**. Circle the number beside the statement that best describes you. Please do not skip any items.

1. Does not describe me at all	2	3	4	5. Describes me very well	
1. My hopes are shattered.....	1	2	3	4	5
2. I have learned to cope better with life.....	1	2	3	4	5
3. I have little control over my sadness.....	1	2	3	4	5
4. I worry excessively.....	1	2	3	4	5
5. I frequently feel bitter.....	1	2	3	4	5
6. I feel like I am in shock.....	1	2	3	4	5
7. Sometimes my heart beats faster than it normally does for no reason.....	1	2	3	4	5
8. I am resentful.....	1	2	3	4	5
9. I am preoccupied with feeling worthless.....	1	2	3	4	5
10. I feel as though I am a better person.....	1	2	3	4	5
11. I believe I should have died and he or she should have lived.....	1	2	3	4	5
12. I have a better outlook on life.....	1	2	3	4	5
13. I often have headaches.....	1	2	3	4	5
14. I feel a heaviness in my heart.....	1	2	3	4	5
15. I feel revengeful.....	1	2	3	4	5
16. I have burning in my stomach.....	1	2	3	4	5
17. I want to die to be with him or her.....	1	2	3	4	5
18. I frequently have muscle tension.....	1	2	3	4	5
19. I have more compassion for others.....	1	2	3	4	5
20. I forget things easily, e.g. names, telephone numbers.....	1	2	3	4	5
21. I feel shaky.....	1	2	3	4	5
22. I am confused about who I am.....	1	2	3	4	5
23. I have lost my confidence.....	1	2	3	4	5
24. I am stronger because of the grief I have experienced.....	1	2	3	4	5
25. I don't believe I will ever be happy again.....	1	2	3	4	5
26. I have difficulty remembering things from the past.....	1	2	3	4	5
27. I frequently feel frightened.....	1	2	3	4	5
28. I feel unable to cope.....	1	2	3	4	5

1. Does not describe me at all
2. Does not quite describe me
3. Describes me fairly well

4. Describes me well
5. Describes me very well

29. I agonize over his or her death.....	1	2	3	4	5
30. I am a more forgiving person.....	1	2	3	4	5
31. I have panic attacks over nothing.....	1	2	3	4	5
32. I have difficulty concentrating.....	1	2	3	4	5
33. I feel like I am walking in my sleep.....	1	2	3	4	5
34. I have shortness of breath.....	1	2	3	4	5
35. I avoid tenderness.....	1	2	3	4	5
36. I am more tolerant of myself.....	1	2	3	4	5
37. I have hostile feelings.....	1	2	3	4	5
38. I am experiencing periods of dizziness.....	1	2	3	4	5
39. I have difficulty learning new things.....	1	2	3	4	5
40. I have difficulty accepting the permanence of the death.....	1	2	3	4	5
41. I am more tolerant of others.....	1	2	3	4	5
42. I blame others.....	1	2	3	4	5
43. I feel like I don't know myself.....	1	2	3	4	5
44. I am frequently fatigued.....	1	2	3	4	5
45. I have hope for the future.....	1	2	3	4	5
46. I have difficulty with abstract thinking.....	1	2	3	4	5
47. I feel hopeless.....	1	2	3	4	5
48. I want to harm others.....	1	2	3	4	5
49. I have difficulty remembering new information	1	2	3	4	5
50. I feel sick more often.....	1	2	3	4	5
51. I reached a turning point where I began to let go of some of my grief.....	1	2	3	4	5
52. I often have back pain.....	1	2	3	4	5
53. I am afraid that I will lose control.....	1	2	3	4	5
54. I feel detached from others.....	1	2	3	4	5
55. I frequently cry.....	1	2	3	4	5
56. I startle easily.....	1	2	3	4	5
57. Tasks seem insurmountable.....	1	2	3	4	5
58. I get angry often.....	1	2	3	4	5
59. I ache with loneliness.....	1	2	3	4	5
60. I am having more good days than bad.....	1	2	3	4	5
61. I care more deeply for others.....	1	2	3	4	5