

PARTNERS IN GRIEF:
COUPLES' NARRATIVES OF THE TRANSITION FROM PEDIATRIC PALIATIVE
CARE INTO BEREAVEMENT

by

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Abstract

A deep interest in how relationships, specifically romantic partnerships, cope with and survive tragedies, guides this research. My research question was: What are the narratives of intact bereaved couples whose children have died after receiving palliative care for a life-limiting illness? Five couples were interviewed who had lost their children ranging in age from 1-14 years of age. This loss occurred between 2 to 9 years previous to this study.

The purpose of this narrative research study was to better understand the ways in which intact marital partners/couples coped together with the stress and grief involved in having a child with a life-limiting condition and then having that child die after receiving palliative care. A secondary aim was to bring forth their voices through their narratives as a means to address the stigmatization and isolation often experienced by those who are bereaved, especially those who have lost a child. This project informs professionals who are working with couples undergoing the struggle of a child's critical illness or who are working with bereaved couples.

Each couples' narrative account was written in story format. In addition to the rich information gained from reading the holistic stories, 5 themes emerged through a categorical content analysis which were: 1) the last thing you worry about are issues about us, 2) accommodating one another's coping, 3) recognizing sources of support and limitations, 4) two souls against the world, and 5) we have a common bond: lessons and legacy of the child.

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Dedication

Dear Lynn,

Why did you have to die? That question will never be answered. I never realized how strange, sad, and full of suffering life could be until you died at the age of 25. I was only 18 at the time and slowly coming into myself. You did so much in your short time on earth but what sticks out the most is how you loved. It was a full love; being a very lucky recipient of it, I know that it was the type of love that fills up every inch of a space and made me feel like I had scored the best sister. It was you who provided the most invaluable lessons to me with your honest way of being, your expressiveness, your creativity, your vibrancy, and that beautiful mix you had of strength and vulnerability.

There have been days where my grief has felt so broad and heavy that it is as though I have the steepest mountain to climb in order to find relief. I've wondered: How am I going to persevere? But when I've looked up, you're there perched on top of the mountain smiling and cheering me on, challenging me to dig deep into my pain and find my inner strength to keep moving. Because, of course, as people say, you can't go around emotions, you have to go through them. Your encouragement and aliveness is helping me do the work I need to do to realize my dreams. Knowing that you're there with me through all of this has allowed me to find the positives in living without you alive and has helped me grow and mature.

It is your death that sparked my interest in researching how families and individuals deal with a young person's death but it is how you lived that gives me the energy to carry out this work.

Dear Dad and Mom,

You two are my best friends and words could never capture the deep love and appreciation I have for both of you. Our connection is what keeps me going. This work is just as much yours as it is mine. I am so sorry that we lost Lynn. Let's make sure to always keep the memory of her alive.

Dear Tommy,

Your determination has always inspired me but more than that, I will be forever grateful that I have a brother who values family as much as you do. You are a kind, generous soul and I love you very much.

CHAPTER ONE

Introduction

When a child does not survive a life-limiting illness the silence of shock and sadness is loud. It is as though the community is protesting and saying in their silence that children should not die. Unfortunately, the deafening silence can make the voices and cries for help of grieving families unheard and their suffering worse (Rallison & Moules, 2004). When men and women become mothers and fathers, their status change and their new identities and roles are supported and celebrated by friends and family. Practical and emotional support is offered with ease. The transition from mother and father to bereaved mother and father is equally powerful, yet this traumatic circumstance is often met with a lack of social support—making the sense of loss more pronounced and more challenging to cope with (Cadell, 2005; Neimeyer, Prigerson, & Davies, 2002). In fact, for parents whose son or daughter dies, the withdrawal of support from hospital staff is often considered a profound secondary loss (Contro, Larson, Scofield, Sourkes, & Cohen, 2004). After the funerals and memorials, friends, neighbors, co-workers, and health professionals move back into their normal lives leaving the bereaved alone with their pain (Cadell; Contro et al.).

As Riches and Dawson (1996a) claim, there seems to be a border between those who are bereaved and non-bereaved. Although the two groups live amongst each other, there is a deeply felt divide. The majority of studies that have investigated the impact of grief on bereaved couples have reported that this divide exists between husbands and wives as well (Hagemester & Rosenblatt, 1997; Kamm & Vandenberg, 2001; Riches & Dawson, 1996a). Gilbert (1996) explains that it is common for family members to experience contrasting styles when dealing with grief and this is especially true for husbands and wives. These

different grief reactions, evidently, can result in frustration, disharmony, and sometimes separation for bereaved couples (Farnsworth & Allen, 1996; Schwab, 1992). This appears to be the dominant story in the research literature.

Statement of Problem

We hear of relationship strain and separation but know little about the lives of bereaved couples who remain together following the death of their child. The reality is that most bereaved couples *do* stay intact after a child's death, and some report that the marriage has strengthened and grown (Lehman, Lang, Wortman, & Sorenson, 1989; Schwab, 1998). Perhaps another reason why we do not know more about couples who have survived a child's death is because the research in this area is mostly about bereaved mothers, leaving the stories and experiences of bereaved fathers unknown or even misunderstood (Davies, Gudmundsdottir, Worden, Orloff, Sumner, & Brenner, 2004; Gilbert & Smart, 1992). Studies that have gathered data from bereaved couples have generally been quantitative in design and have focused on and reported mainly negative outcomes (Kamm & Vandenberg, 2001; Lehman, Lang, Wortman, & Sorenson; Schwab, 1992). Although these studies have made a substantial contribution, we need to know more about the meaning of bereavement processes and positive as well as negative experiences.

Another deficiency in the literature, and one that I will attempt to address, is that the stories of intact bereaved couples who have transitioned from pediatric palliative care (the care given to patients whose disease is not responding to curative treatment) to bereavement has never been explored. Ethical and medical aspects of treating dying children are the main foci in the pediatric palliative care research literature. Psychosocial research has typically concentrated on individuals (the patients, siblings, or individual parents) or the family but not

on the dyadic parental unit. Additionally, most of the literature that attends to the psychosocial components of palliative care for children is conceptual rather than empirical. To address this dearth in the literature, I have completed a qualitative study that used narrative methods to document the stories of bereaved couples whose child died from an illness.

In addition to reviewing the literature, my personal experiences working with families on a pediatric cancer ward have led me to believe that these parents do not get enough support. The focus of health professionals is on the sick child despite the fact that family-centered care is considered the standard for pediatric practice in North America (Gilmer, 2002; Himmelstein, 2006). Additionally, parents in this situation are not only dealing with systems outside of the family but are also often dealing with being part of a spousal subsystem. The spousal relationship may be a place of comfort and support or difficulty during a child's illness and after the child dies.

Purpose of Study and Research Question

The purpose of this narrative study was to document, describe, and understand the lived experiences of couples who have stayed together throughout their child's illness and death, and are now on the journey of bereavement. The participants for this study were recruited by Canuck Place, the Vancouver children's hospice. The research question for this study was: What are the narratives of intact bereaved couples whose children have died after receiving palliative care for a life-limiting illness? Other questions I explored in the interviews were: How do couples prepare for the death of their child as a team? What do their individual and joint processes look like? How do they accommodate one another's coping? How might the couple's bond tighten and their relationship grow in the aftermath of their child's death due to an illness? How might they construct meaning together before and

during bereavement? Through this study, I present a portrait of bereaved couples who have remained intact. This was not a study about marital satisfaction, although that was a part of some of the participants' stories. The interviews were analyzed for expressions of posttraumatic growth (PTG) and meaning-making and this is discussed in the last narrative which is my story as the researcher.

It is hoped that this research study will further our understanding of issues related to couples' loss of their child. The results can be used to inform the psychosocial practices of health care providers (doctors, nurses, social workers, and psychologists) on the importance of giving attention and support to marital partners/couples whose children are dying from an illness. For grief and family counsellors working with bereaved couples, learning what facilitates successful coping and how meaning is made in these relationships would also be very useful. Hopefully this exploratory research will generate more studies in this area and lead to a lessening of the stigma too often placed on grieving parents in the aftermath of a child's death. Finally, it could be helpful for couples who are anticipating their child's death during the palliative care stage of an illness, or who are newly bereaved, to have others' stories to turn to as a means of comfort or guidance.

Conceptual and Theoretical Frameworks

The major conceptual frameworks on which my study was based were family systems theory and relationship-focused coping theory. I will discuss both of these theories briefly as they apply to studying how couples cope. Prior to that discussion, I introduce the ideas and theories about grief that informed me as I collected and analyzed data for the research. The grief theories I drew from all fit into the social constructionist paradigm and thus nicely fit with the narrative methodology used.

Grief Theories

The stories of bereaved parents documented by researchers reveal a common theme of isolation. This is not surprising considering the North American norm of avoiding death and grief in social discourse (Riches & Dawson, 1996). In addition to the anxiety-provoking nature of discussing these realities, possibly what perpetuates this pattern of avoidance is that grief theorists, for a long time, have argued that what is best for the bereaved is to gradually detach themselves from the dead and resume their routines as though nothing happened (Stroebe & Schut, 1999). Thus when a friend of a bereaved parent offers the platitude of “time will heal,” and then changes the topic, they are simply echoing this belief about adaptive grieving. Indeed, this is the goal of what we know as grief work—to process the emotions and thoughts that accompany bereavement and then regroup. In the last couple of decades, a revolution has begun in the field of grief and loss. In response to research that has shown that people usually do not put an end to their relationship with the deceased, nor want to, theorists have passionately disputed the grief work hypothesis (Stroebe & Schut).

Before I discuss the various theories of grief, I want to share some definitions of *meaning-making*. Attig (2001) distinguishes *meaning-making* from *meaning-finding* by emphasizing that meaning-making is about the process of creating meaning; it is a conscious activity that individuals engage in throughout life, especially during significant transitions. Conversely, Attig explains meaning-finding as a passive search for meaning. Neimeyer, Prigerson, and Davies (2002) and Neimeyer (1998) contribute to this discourse adding that meaning-making is not solely a private activity done in the internal world of the bereaved individual but as Neimeyer, Prigerson, and Davies state “at the juncture of self and system” (p. 239). As the bereaved individual begins the journey of making-meaning of their loved

one's death by reconstructing views of self, others, and the world, they involve others to validate their ideas and feelings and to assist them in forming meaning after such a tremendous loss (Neimeyer, Prigerson, & Davies).

You will notice that the theories I describe below persuasively argue that grief is about processing, rather than reaching an endpoint. Given that my research will attempt to understand meaning-making in bereaved couples, it is also helpful to discuss meaning-making in the context of families. Nadeau (1998) used Reiss's model of family meaning-making in her research on families constructing meaning together after a loved one dies. Nadeau discussed Reiss's terms *family paradigm* and *crisis construct*. *Family paradigm* is defined as the family's main organizer and "consists of the family's assumptions, constructs, fantasies, and sets or expectations" (Nadeau, p. 23). The *crisis construct* is a concept closely related to families in bereavement and is described in the following way:

Serious family crisis is likely to occur in response to two universal categories of human suffering: prolonged illness and death. The family in acute crisis is disorganized and not experiencing themselves as a unit, but rather as a collection of individuals. The path to recovery or reorganization of the family begins with the crisis construct, a new form of construct for the family which realizes—at some level—that it is in crisis and begins to develop some shared concept of that crisis (Reiss as cited in Nadeau, p. 24).

It is emphasized in Nadeau's writing that Reiss's crisis construct is not as cognitively-oriented as the term might imply but about the family system's deep emotional responses that "are organized as much by fantasy and longing as by observations and rational inference" (p. 392).

Klass' (2001) definition of grief for bereaved parents reflects the new ideas being put forth: "the purpose of grief has been defined for most of the 20th century as a break in an attachment. In fact, however, the members of bereaved parents do not detach from their child" (p.78). Instead of severing their attachment to the deceased, as some theories suggest, the bereft's relationship with the deceased child usually goes through a transformation where the child remains an important feature in their life (Klass). Walter (1996) agrees that the purpose of grief for the bereaved is to "integrate the memory of the dead into their ongoing lives" (p.7). Walter rejects the notion that the goal of grief is to reach a place of living comfortably without the deceased. Walter proposes a post-modern model that embraces the fact that survivors typically want to talk to people about the deceased. Walter claims people have a never-ending need to make sense of themselves and others in their continually changing life narrative. Bereavement, in Walter's model, is an unlimited and reflexive conversation with self and others and allows for processing of the death and construction of a new story that both involves and does not involve the deceased.

Stroebe and Schut's (1999) Dual Process Model (DPM) of coping with bereavement conceptualizes grief as a dynamic process that involves two types of coping: loss-oriented coping and restoration-oriented coping. The DPM suggests that individuals typically oscillate between ruminating over the loss and being concerned with re-establishing their normal lifestyle. This model, rare because it describes the *process* of coping, contends that the bereaved cycle between confrontation and avoidance and that this is adaptive. On one hand the individual is realizing the loss and on the other, as Stroebe and Schut explain, they are "taking time off from grieving, as when watching an engrossing tv program, reading,

talking with friends about some other topic, or sleeping” (p. 9). In this framework, coping with the loss is embedded into everyday life and does not have a timeline.

As Balk (2004) contends, grief is a “dangerous opportunity” offering both the possibility of growth and development as well as “harm and dissolution” (p. 367). As the Grief to Personal Growth (GPG) theory states, rumination about the loss can indirectly lead to growth (Hogan & Schmidt, 2002). The GPG model was developed using bereaved parents. It suggests that these individuals transition from the despair of grief, which involves intrusive thoughts and ruminating about the loss of the child’s life, to avoidance and, finally, reaching out for social support. Hogan and Schmidt consider this to be the turning point for the bereaved. Once the individual begins opening up to others about their emotional and psychological experience of grief, a transformation of self commences and growth can occur. Like the DPM, this model challenges the grief work hypothesis in that it disagrees with the notion that people want to, or actually experience, a return to normal life, as though the death was an isolated event and that the grief can be dealt with and moved past.

Family Systems Theory

Family systems theory is a theoretical orientation that was useful in framing my study as it emphasizes the relational environment, how that environment influences us and how we influence it. Goldberg and Goldberg (2004) describe family systems theory, which was advanced by Murray Bowen, as one that “emphasizes the family as an emotional unit or network of interlocking relationships best understood from a historical or transgenerational perspective” (p. 508). Several of the concepts and viewpoints of family systems theory have relevance in studying how married couples interactively cope with a child dying and grief that follows—namely, *marital quid pro quo*, *roles*, *rules*, *subsystems*, and *boundaries*.

Men and women play certain roles in the family and their role descriptions might depend on their *marital quid pro quo*: An initial agreement between husband and wife regarding how they will define themselves in relation to the other in their marital relationship (Goldberg & Goldberg, 2004). *Roles* are the expectations assigned to each position in the family. *Rules*, in family systems terminology, can be stated explicitly or implicitly and they “characterize, regulate, and help to stabilize how-and how well-families function as a unit” (Goldberg & Goldberg, p. 74). For instance, a family might have an unstated rule that crying is a sign of weakness. Family systems are made up of *subsystems*, one being the *spousal subsystem*. For bereaved couples who have multiple children, their spousal subsystem has the largest influence on the family; it teaches children about intimacy, commitment, and accommodating other people’s needs (Goldberg & Goldberg). Essentially the husband-wife dyad has the power of holding the family together or making it disintegrate.

Also relevant to a study about bereaved couples is the family systems notion of *boundaries*. A boundary is “an invisible line of demarcation that separates an individual, a sub-system, or a system from outside surroundings” (Goldberg & Goldberg, 2004, p. 85). Boundaries determine how much information can flow between systems and also who is considered a member of a particular system. Boundaries, determined by family rules, can be clear, blurry, or rigid; they can be open—allowing for an easy flow of information out and in—or closed. For example, a bereaved couple with clear and open boundaries might let helpful friends and family members prepare their child’s funeral and can easily let these supportive people know that they do not want visitors at the house for awhile. Conversely, a bereaved couple with rigid boundaries might have difficulty letting others, and one another, “in.” Perhaps they each learned in their families-of-origin that sharing one’s emotions can

make you vulnerable. The ability to comfortably express one's emotions is important both in the grief process theories and family systems (Traylor, Hayslip, Kaminski, & York, 2003).

Family systems theorists view families as talented at maintaining *homeostasis*. Goldberg and Goldberg (2004) describe it as "a dynamic state of balance or equilibrium in a system, or a tendency toward achieving and maintaining such a state in an effort to ensure a stable environment" (p. 509). So what happens when a trauma, such as a child dying from an illness, occurs? Nadeau (1998) theorizes a death in the family is powerful enough to disturb homeostasis.

Relationship-Focused Coping Theory

Another conceptual framework that underlies this study is relationship-focused coping theory. It is compatible with family systems theory in that the focus is on the relational context in which we all exist. Conceptualizations of coping typically have concentrated on problem-focused (attempting to change the situation itself) and emotion-focused (managing negative emotions that have been produced by the stressor) strategies (O'Brien & Delongis, 1996). Recently, the understanding of coping has been expanded to include an interpersonal aspect, known as relationship-focused coping (O'Brien & Delongis). Since bereaved couples experience grief in the environment of their relationship, it is meaningful to have some roadmap for understanding how they might cope together; essentially, what works and what does not. Relationship-focused coping refers to methods that aim to preserve and manage a relationship during stressful periods. As O'Brien and Delongis report, successful coping does not only involve finding solutions and dealing with emotions, but ensuring that one's important social relationships are maintained, especially when the stressor occurs in a dyadic context.

It has been found that helpful relationship-focused coping is using three strategies: empathy, accommodating the other person's coping methods, and compromising (O'Brien & Delongis, 1996). Badr (2004) discusses complementary relationships. For instance, in a heterosexual relationship, the man might use more problem-focused strategies, whereas the woman might be more emotion-focused. As long as both partners are actively engaged in the process, their different methods of coping will be complementary. In a sense, this is similar to how the DPM depicts adaptive coping—the individual moves back and forth between the emotions of grief and dealing with the practicalities of daily living in the midst of loss. Hindering relationship-focused coping might involve confronting, ignoring, blaming, or withdrawing (O'Brien & Delongis). This theory has yet to be applied to bereaved couples. My study will do just that. Since the literature shows that couples generally have difficulty because men and women often grieve differently, perhaps applying the relationship-focused coping theory to bereaved couples will assist in re-conceptualizing couples' differential grief reactions with less pessimism and worry.

CHAPTER TWO

Current Research Knowledge

The literature review that follows includes the following: studies on pediatric palliative care; studies on the impact of child loss on parents, research on how the family system deals with grief; studies that investigated marital dyads dealing with illness, and concludes with studies that focus on bereaved couples. Again, the purpose of my study is to document, describe, and understand the lived experiences of couples who have stayed together throughout their child's illness and eventual death and now on the journey of bereavement. This review of the current research will reveal what has already been explored, where my study fits in and what gaps in the literature my research intends to fill.

Pediatric Palliative Care

For parents of dying children, grief begins before the child's death. Those families who must encounter the culture of pediatric palliative care deal with their emotions surrounded by other families and hospital or hospice staff. Contro et al. (2004) interviewed 68 family members of deceased children to hear what they had to say about treatment, palliative care, and bereavement follow-up contact. The researchers also surveyed 466 staff members and community physicians to learn about their comfort and expertise in delivering end-of-life care for children. The themes that emerged from the interviews with families include ineffective or inadequate communication and support from hospital staff, the challenges inherent in witnessing a child in pain and having it not be properly managed, and not enough follow-up after a child's death. These findings alert us to the many needs parents have in and after pediatric palliative care and also might make one wonder: "When should the care for the family end?"

Two non-empirical pieces of literature are informative regarding the difficult nature of the practice of caring for dying children. Rallison and Moules (2004) use the metaphor of a cloak to describe how pediatric palliative care is often not talked about and purposely avoided and ignored—it is covered by a cloak because many people, including health professionals, are not comfortable with the idea that children die. Rallison and Moules talk of the ‘unspeakable’ nature of pediatric palliative care. They strongly argue that families are the unit of care, and that to empower them we must enable them to put words to their suffering and break free of the silence. Rallison and Moules suggest that “the cloaking and shrouding of the child and family silences the family’s voice and hampers the ability to talk openly and creatively about the situation” (p. 294). Does the cloaking of feelings of grief make it difficult for couples in pediatric palliative care to speak within their relationship about their emotions?

Himmelstein (2006) explains that pediatric palliative care focuses on alleviating the suffering and enhancing the quality of life for both the young patient *and* the family. Himmelstein describes this type of care as being extremely complex for both the health care providers and families because they are dealing with a myriad of issues: physical, psychosocial, and spiritual concerns, advanced-care planning (e.g., who are the decision-makers, do-not resuscitate orders), and practical concerns, such as finances. Himmelstein writes that ethics and decision-making are a large part of the process, just as it would be for an adult dying from an illness. However, in addition to the practical and ethical considerations, families are dealing with anticipatory grief and being forced to accept the fact that a child is dying.

Furthermore, little is known about the experiences of fathers who endure a child's illness and death. Davies et al. (2004) hoped to shed light on fathers' experiences of having a child die from a life-limiting illness. This study, which used grounded theory methods, involved in-depth interviews with 8 fathers whose children received care at a hospice before dying. Davies et al. use the metaphor of "living in the dragon's shadow" to describe what it is like for these fathers. The researchers found that these men battled with uncertainty, responsibility, and disruption to everyday life. Their perception of the role demands of father and husband also had an impact on how they experienced their child's illness and death. Marital relationships were under considerable strain and the researchers found that each father had wishful thoughts about escaping the situation but none ever did. This interview excerpt reflects how distant from normal life parents in pediatric palliative care can feel:

You feel that you've been taken out of your life and put into somebody else's movie . . . the wrong movie. Like if you were watching a film in the theatre and when they change the reels, they put on a reel from a different movie . . . it's that disorienting. It's a very alienating experience. (p. 121)

After a child dies from an illness, what happens in the years after the death for the family? Martinson, McClowry, Davies, and Kuhlenkamp (1994) conducted a longitudinal follow-up study of 48 families who had lost a child to cancer 7-9 years prior. This empirical study which involved the family members filling out questionnaires and being interviewed showed the impact of death on a family. Some participants reported feeling stronger and more prepared for life's obstacles, whereas others reported being hypervigilant and fearful because of how the child died. Some marriages dissolved and other couples chose to have another child. Siblings of the deceased reported double-losses: Loss of their brother or sister

and temporary loss of parents who were involved with care-giving. For all participants, family became more of a priority.

Studies of Impact of Child Loss on Parents

Do bereaved mothers suffer more than bereaved fathers? Females are socialized in our society to be emotion-oriented, the nurturers and caregivers (Brown & Gilligan, 1993). Moreover, historically and universally, mothers are seen as symbols of care-giving. In a study that explored the experience of mothers' bereavement from a feminist perspective, Farnworth and Allen (1996) interviewed 10 bereaved mothers and found that the societal, family, and couple context was a place of marginalization for them. Most of the women expressed that having their child die was dismantling, disorienting, and devastating. Expected by themselves and society to be protectors of children, the mothers had a troubling time with their roles and identity after their children died. The women shared an experience of a having a lack of emotional support and understanding from their partners. For one of the participants, divorce came after realizing that her needs during grief could not be met. This excerpt from that interview is illuminating:

A week after Charlie died, he was like, "Are you going back to work? Are you going back to work?" Well, I felt like he was pushing me in a corner, smothering me. . . . he just couldn't understand anything like that [her emotions], so he just took it upon himself to start running, you know, instead of sitting there looking at me crying, or trying to go to help me. I asked him to go get therapy with me. . . . It just ended our marriage. (p. 363)

Other participants reported that they sought support outside their marriage when they decided their spouses could not supply what they needed.

Znoj and Keller (2002) hypothesized that, compared to their non-bereaved gender-matched peers, bereaved parents would experience much more mental and physical distress. One-hundred and seventy-six bereaved parents answered questions on four scales. The researchers found that 46% of all the bereaved mothers experienced deterioration in their physical health since their child's death compared to 28% of the bereaved fathers. The control sample showed no difference in physical health for males and females, and their general health status was significantly better. Also, the bereaved parents had clinically elevated levels of depression, with the bereaved mothers reporting higher depression scores than the bereaved fathers. It would not be a huge leap to surmise that enduring individual emotional and physical turmoil could put quite a strain on a bereaved couple's relationship.

Many people might have difficulty imagining that an event that violates the natural order could result in positive outcomes. Surprisingly, bereaved parents, compared to other bereaved individuals, are the most likely to experience growth (Nolen-Hoeksema & Larson, 1999). This is counter-intuitive but perhaps parents are more likely to engage in a process to find positives in their child's death *because* it is such a strange and awful event. Nolen-Hoeksema and Larson found that bereaved people who perceived something positive in their loss by 6 months following the death of a loved one had lower levels of distress at 6, 13, and 18 months post-death than people who had not found something positive. This study involved 455 participants whose family member had died. Fifty-four were mothers of the deceased and 11 were fathers. Everyone in the study filled out questionnaires and were interviewed. One-hundred percent of the parents whose child had died 13 months earlier were able to find something positive in the loss; this was a much higher percentage than any other bereaved group. Nolen-Hoeksema and Larson speculate that "Parents who lose a child

may need more than any other family group to construct some positive meaning and consequence from their loss to overcome the sense of injustice and confusion they feel over losing their child” (p. 156).

Like Nolen-Hoeksema and Larson (1999), Cadell (2005), inspired by Tedeschi and Calhoun’s (2004) work on posttraumatic growth, found that bereaved parents can grow from coping with the trauma of losing a child. Cadell interviewed and administered questionnaires to 12 bereaved parents (mostly mothers), and learned that growth was common amongst the group. These parents, who lost a child 1.5-17 years before the study, reported feeling more capable of coping with life’s difficulties, stronger, and more compassionate towards others. Wheeler (2001) also found that, of the 166 bereaved parents who answered questionnaires, the majority had searched for and found meaning in their child’s death. Riches and Dawson (1996a) describe a similar phenomenon and note that most of the 31 bereaved parents they interviewed found meaning with others in the bereaved parent community. Braun and Berg (1994), after studying meaning reconstruction in the lives of 10 bereaved mothers, note that the ability to restore meaning after a child’s death depends on a previous meaning structure that could “account for and ‘place’ a child’s death” (p. 105). The mothers in Braun and Berg’s grounded theory study evidently went through three phases in the process of meaning construction: Discontinuity, disorientation, and, then, adjustment.

Despite the fact that none of these studies looked at bereaved couples as a unit, their findings could be promising and hopeful for couples who have a lost a child. We can infer that if bereaved mothers and fathers grow and reconstruct meaning individually after their child’s death, they might also do so as a team.

Family Systems and Grief

Does the grief process affect the characteristics of relationships within a family system or do the characteristics of a family affect the experience of grief symptoms?

Traylor, Haylsip, Kaminski, and York (2003) explored the dynamic between grief processes and family systems. Sixty-one people whose parent or spouse had died shortly before the study filled out questionnaires to assess their grief symptoms and characteristics of the relationships within their family 4-5 weeks after the death. They found that emotional interaction within a family was a critical indicator of overall functioning for the whole family, as was family cohesion. The families where affect was easily communicated had an easier time processing grief. These results suggest that accommodating emotional expression for the bereaved is extremely beneficial to them, especially if you are related to the bereaved person.

Do family members create meanings of an event together? Nadeau (1998) suggests that many researchers have questioned whether family meanings do exist. Nadeau's research proves that they do and that they tend to arise from family discourse, or 'family speak.' Responding to a void in qualitative family grief research, Nadeau (1998) studied 10 multigenerational, grieving families. Working from a family systems perspective, Nadeau hoped to gain an understanding of how families make meaning of their loss together. Instead of simply questioning how individual members dealt with the loss or made meaning of the death, Nadeau inquired about how these families interactively understood and processed the death. Nadeau found that these 10 bereaved families, in a variety of ways, made sense of death as a family unit. When a family member dies, we cope in the context of relationships.

Strength in a spousal subsystem likely leads to family stability. Thus, it is valuable for us to consider how the family system, especially the spousal sub-system, reacts to a child's death.

Coping in Marital Dyads

How do couples cope together during crises? The finality of a child's death differs greatly from the possibility of an adult dying from a chronic illness. However, if we are concerned with how partners in a romantic relationship deal with crises, Badr's (2004) inquiry into coping in marital dyads serves as a knowledge-builder. Badr sought to discover how two partners in a romantic relationship jointly cope when one partner has a chronic illness. Ninety healthy couples and 92 couples where one spouse had a chronic illness answered questions on the Relationship-Focused Coping Scale (O'Brien & DeLongis, 1996) and the Brief COPE (Carver, 1997). In their findings, active engagement involved "partners becoming actively involved in decision-making and other problem solving activities" (Badr, p. 198). Protective buffering is described as the "extent to which partners deny anxieties and concerns, put on a brave front, or defer to their partner to avoid disagreements" (Badr, p. 198). The results of the investigation showed that if husbands and wives were congruent in their use of active engagement and complementary in their use of protective buffering and avoidance coping, their relationships were able to adapt well to the situation.

What are couples' narratives during stressful periods? Couples' illness-narratives were the focal point in Walker and Dickson's (2004) study. Fifty-three couples were interviewed together and completed questionnaires to examine how couples talk about illness, and how illness issues related to their marital interaction. Five different couple types emerged from the data: the sympathetic couple, the independent couple, the mixed couple, the nonreciprocal couple, and the rejecting couple. Reminiscent of Badr's (2004) findings

and relationship-focused coping theory, couples in Walker and Dickson's study were most successful at handling problems when they were able to openly communicate with each other and adjust to meet the needs of their spouse. The findings from this study suggest that couples create narratives and that these narratives not only demonstrate how a couple functions together but that they are shaped from culturally and socially determined scripts.

Bereaved Couples

The death of a child for a couple illuminates the fragility of life and can call into question how much the relationship can withstand. To use Tedeschi and Calhoun's (2004) metaphor, traumatic events are like earthquakes: shaking up and threatening to shatter one's understanding of the world, ability to make decisions, and sense of meaningfulness. To take the metaphor further, bereaved parents might inquire: What will this seismic event do to our relationship?

Intimacy is multidimensional and includes intellectual, sexual, recreational, social, emotional, and spiritual intimacy (Schaefer & Olson, 1981). In a qualitative study with a social-constructionist perspective, Hagemester and Rosenblatt (1997) interviewed 24 couples who had lost a child 1-32 years prior and uncovered their stories of sexual intimacy following the death. Hagemester and Rosenblatt sought to discover the meanings couples attributed to sexual intimacy and its absence during bereavement. Consistent with social-constructionist perspectives, the meanings that both people in the partnership gave to sexual intercourse and sexual touching usually was linked to their ability and interest in getting intimate with their partner. Sixteen of the 24 couples reported difficulties with intimacy which resulted in some relationships ending. Sexual intimacy for some of these pairs produced guilt, feelings of emptiness, and intense feelings about the loss. Thus far, this is the

only study that has investigated the meanings attributed to sexual intimacy for bereaved couples.

Lang, Gottlieb, and Amsel (1996) discovered that husbands and wives typically experience grief differently. The researchers had 31 bereaved couples who lost an infant child 2-4 years prior to the study fill out questionnaires measuring their bereavement experience, somatic functioning, and intimacy in their relationships. Thirty-six non-bereaved couples completed these tests as well. Bereaved husbands reported less guilt, meaninglessness, yearning and fear than their wives. After a follow-up, it was found that those dyads that had lower intimacy scores experienced more intense grief. Again, it is clear that intimacy is a complicated and important aspect in the relationship of bereaved couples.

Schwab (1992) found that the death of a child can put a couple's relationship in danger. Interested in determining what the passage of time would do to bereaved couples' relationships, Schwab interviewed 20 heterosexual couples one month and then four years after their child's death. This study provided longitudinal data on this population and filled a void in the literature. For all participants, their child's death was the most devastating thing they ever experienced and the main themes that emerged spoke of marital relationship problems, including: fathers' worry and frustration over wives' grief, wives' anger over husbands not being emotional enough, communication difficulties, and decrease or loss in sexual intimacy. Withdrawing from one another, for all of these reasons, was commonly reported. It seems as though bereaved couples might have struggles around attending simultaneously to their own intense pain and their spouse's. Since I am interested in the life of bereaved couples, this study serves to build my knowledge about what can happen in the years following the death.

Kamm and Vandenberg (2001) explored whether speaking about grief helped couples cope with it and feel more satisfied in their relationship. Thirty-six couples who had experienced the death of a child filled out questionnaires about communication, grief reactions, and marital satisfaction. Similar to Schwab's (1992) finding, the women in this study preferred when their male partners were expressive about their grief and this led to marital satisfaction for the women. The main finding in Kamm and Vandenberg's study was that positive attitudes about communication resulted in greater grief in the earlier stages for the couples but lower levels of grief in the long run. Similar to Traylor, Hayslip, Kaminski, and York's (2003) finding about grieving families, the dyads who did not value open communication about the loss experienced greater grief consistently for a longer period of time. Although not discussed in this article, one could hypothesize that for the relationships where one or both individuals were experiencing high levels of grief and did not feel comfortable expressing it, this could lead to marital disharmony and perhaps separation.

It may be that the relationships of bereaved couples are not as different from the relationships of non-bereaved parents as we would think. Najman, Vance, Boyle, and Embleton (1993) concluded that bereaved couples and non-bereaved couples do not differ in terms of quality of their marital relationship. They did a follow-up study with 809 parents 2 months and 6-8 months after their infant died of an illness. Although there was an increase of marital breakups immediately after the death, for those couples who stayed together, at 6 months post-death there were no longer any marital adjustment differences compared to those couples whose infant survived.

After an extensive search, only three studies emerged that revealed couples' growth and/or strength following bereavement. Lehman, Lang, Wortman, and Sorenson (1989)

gathered data from 54 parents whose 1-28 year old child died in a motor vehicle accident 4-7 years prior to the study and 61 matched controls. Although 21% of the married couples reported that their marriage had weakened because of the loss, 29% said their marriage had improved. This quote from an interview with a bereaved mother captures this positive outcome:

Her death has brought us closer together. My husband is more compassionate and listens to me more. More in tune to my feelings than before and the pain and harshness of the type of death has strengthened the marriage. We've been able to communicate so much better than before. (pp. 355-356)

In two projects most similar to this study, bereaved couples' relationships emerged as difficult or stable. Narratives created by 12 couples who lost children to vehicle accidents, natural disasters, accidents, illness, at childbirth, and through murder, were analyzed by Riches and Dawson (1996b). Riches and Dawson found that relationships "lay at the heart" (p.361) of nearly all of the parents' stories and that the degree to which their partner, other family members, friends, colleagues, and health professionals provided a sympathetic audience to grieving was prominent in the participants' narratives. Riches and Dawson learned that in marriages where partners were uncritical and listened supportively to each other's grief story, the couple relationship was described as strong. The experience of the married relationship being a source of strength and support was true for several of the couples in this research project.

Gilbert and Smart (1992) collected data from interviews with 27 bereaved couples to learn about dyadic coping in marriages where an infant or fetal death occurred. They discovered that social support, particularly within the couple relationship, contributed to

making meaning and healing for the participants. Gilbert and Smart found that although most couples in the study went through an initial period of instability and marital strain, it was followed by an increased sense of stability in the marriage. This excerpt from an interview shows the strength that can exist in a marriage where a child has died:

There's another human being there sharing this with you. I suppose the idea is it's being shared. It helps. I guess that would be the main strength that she was able to give me was that there's someone here that loves me and also loved Timmy, and I love her and vice versa. (p. 76)

Summary of Literature

When a parent's world is shattered by their child's death, how can they rebuild their life? Social support seems to be integral in the grieving, meaning construction, and growth processes. If intimacy and social support allow us to make meaning of child loss (Nadeau, 1998; Riches & Dawson, 1996), then paying attention to how bereaved couples come together, rather than break apart, is important. Tedeschi and Calhoun (2004) opine that "the degree to which individuals engage in self-disclosure about their emotions and about their perspective on the crisis, and how others respond to that self-disclosure, may also play a role in growth" (p. 7). My assumption is that when couples who have lost a child communicate openly with each other about their grief, and listen with empathy, they are creating a fertile ground for four positive potential outcomes: (1) achieving intimacy and relationship satisfaction, (2) decreasing isolation that often accompanies grief, (3) making meaning through their narratives, and (4) experiencing posttraumatic growth.

It is clear after reviewing the literature that most of the problems bereaved couples face are in the areas of communication and intimacy. It is apparent that disparate grief

reactions and intimacy needs can cause couples to question if their relationship can handle bereavement. However, based on the beliefs about adaptive coping in both the DPM and relationship-focused coping theory, contrasting styles may be beneficial interpersonally. Partners in a relationship might find that they learn adaptive coping methods from each other. A partner who has a tendency to ruminate and be very affect-oriented might benefit from having a husband or wife who is inclined to be focused on daily living activities (e.g., finding a good movie to see). The partner who is more likely to confront the emotions of loss might help their spouse process their grief. If a husband and wife have complementary coping styles, and accommodate each partner's grief reactions, the support they offer to one another could result in individual and interpersonal meaning-making and growth. Actively engaging in problem-solving by seeking social support, as well as expressing emotions to others, allows people to find something positive in their grief (Nolen-Hoeksema & Larson, 1999). The grief theories discussed above illustrate the importance of rumination *and* moving forward. Therefore, if bereaved couples are able to reorganize their life together so that they validate each other's grief reactions and spend time both confronting the death and restoring their daily routines, their relationship should be able to handle the tragedy.

As Klass (2001) emphasizes, it is important for bereaved parents to keep their deceased child's spirit alive and they can achieve this by interacting with people in their community who recognize the death, are mourning it, and where a continuing bond with the child is validated and shared. Before walking into the community for support, bereaved parents grieve first with close family members. Parents who have multiple children may find that how they grieve has a significant impact not only on their spouse but on their other children. As Nadeau (1998) found, family members do process grief together. Parents serve

as models for children and the strength of the spousal system can lead to family stability.

This is important to emphasize because bereaved parents are often coping both in the context of a marital relationship and within a family system including other children. My study will focus on bereaved parents' marital relationships and explicate the relationship processes that take place in the midst of pediatric palliative care and grief, as well as everything and everyone else in their lives.

CHAPTER THREE

Method

What are the narratives of intact bereaved couples whose children have died after receiving palliative care for a life-limiting illness? Narrative inquiry was used to answer this research question. This method was chosen because the goal of my research was to look specifically at the stories constructed by bereaved couples. My interest in meaning-making also led me to select an approach that would invite the participants to tell their stories. Oral narratives are opportunities for retrospective meaning-making (Chase, 2005). Narrating one's biography is an event where the person ". . . shapes, constructs, and performs the self, experience, and reality" (Chase, p. 657). Joint construction of relational stories can illustrate a couple's mutual thoughts about the emotional nature of their relationship (Gergen & Gergen, as cited in Walker, Dickson, & Orbuch, 2004), and, I believe, are dynamic performances of themselves as partners.

Gilbert (2002) suggests that narrative approaches and grief research complement each other because stories bring together the elements of experience, thoughts, and feelings, and that people have an urge to develop stories to make order out of chaotic, possibly insensible, events such as major losses and traumas. Gilbert, as well as Tedeschi and Calhoun (2004), posit that narratives of trauma and survival are important to survivors because it forces them to confront questions about meaning and how to reconstruct meaning in their worlds after loss. Bosticco and Thompson (2005) assert that for individuals in grief and bereavement story-telling has these positive, and sometimes healing, functions: sense-making and catharsis. Riches and Dawson (1996b) state that bereaved parents, particularly in talking about their child's death, are involved "in an essential creative process which allows parents

to draft, re-edit and rewrite their new and apparently meaningless status” (p. 360) and that having a sympathetic audience is crucial.

Participants

Five couples agreed to participate in this study. I decided to use this number of participants because I expected the in-depth interviews with the 5 couples to provide me with sufficient data as well as the type of data that I was looking for. The counsellors at Canuck Place generously helped me recruit by sending out letters of invitation to bereaved couples they knew. They sent out letters to 20 couples who they thought would qualify and I initially heard back from 2 interested couples. To achieve the objective of interviewing 4-5 couples, the Canuck Place staff and I decided to send out reminder letters to the group as well as letters of invitation to a new group of 11 bereaved couples. After this mail-out, I got telephone calls from 3 couples who expressed interest and agreed to take part in the study. The participation was voluntary and the participants contacted me first. The main inclusion criteria for the project were: (1) couples who are currently married/common law and were together at the time that their child was diagnosed with a life-limiting illness; (2) they self-describe as being “intact;” (3) their child was diagnosed with a life-limiting illness, received palliative care, and died, (4) it has been at least 1 year since the death and (5) they can speak, read, and write English. The exclusion criteria were: (1) couples who are separated or considering separation; (2) couples where one or both people are experiencing extreme grief reactions; (3) couples where only one person is willing to engage in the study interview, and (4) couples whom I know from working on the cancer ward at British Columbia Children’s Hospital.

Procedures

As stated above, participants were notified of the study by a letter of invitation which was given to them by a member of the staff and a counsellor at Canuck Place. The couples who were interested and available to participate were sent the letter which described the study and it included my telephone number and e-mail address. The potential participants had to make the initial contact. When they telephoned, I described the project to one of the partners and determined their interest and their partner's in participating and screened for the inclusion criteria. The calls served also as a way to begin the rapport-building process. I asked them to tell me a little bit of their story (e.g., When their child died, name and age of child, how they are doing now). I then set up interviews with those who were interested, along with their consenting partner, at a day, time, and place that was convenient for them. I interviewed one couple at Canuck Place in the cozy, quiet music room and the other couples at their homes. Finally, I reminded the participants that the interviews would be about their processes as a couple and encouraged them to spend some time reflecting, writing, or talking with their partners about what they might want to include in the narratives they would be sharing with me.

Each participant (including each person in a couple) was required to sign a consent form before I began the interview. The interviews were conducted with both spouses present and each interviews lasted about 1.5 hours (with the exception of one couple who I met with for 3 hours), ensuring that enough data was collected and so that there was sufficient time for each story to be fully told. The interviews were audio-taped and the audio-tapes were transcribed almost immediately after the interviews. The interviews were developed to answer a broad question which invited a story, as suggested by Reissmann (1993) in her text

on narrative analysis, and there were some facilitating questions to assist the participants in elaborating on their story (see Appendix E, the Interview Guide). The transcriptions and summaries of their narratives were sent to each couple in order to verify the data.

Transcription

Transcribing discourse, like photographing reality, is an interpretive practice.

Decisions about how to transcribe, like decisions about telling and listening, are theory driven and rhetorical . . . Different transcription conventions lead to and support different interpretations and ideological positions, and they ultimately create different worlds. Meaning is constituted in very different ways with alternative transcriptions of the same stretch of talk. (Riessman, 1993, p. 13)

Lapadat and Lindsay (1999) emphatically discuss how transcription is an interpretive process and that, when transcribing, we need to be aware of the contextual factors at play in the production of speech. Contextual factors include participants' histories and roles, details about the interview setting, as well as cultural factors. Essentially, Lapadat and Lindsay state that transcription is subjective and that it is important as a researcher to make known the transcription key (e.g., coding for pauses, loudness, animated tone). I believe that transcription is part of the analysis and thus, was as reflexive as I could be when transferring the data from the audiotapes onto paper. I made note in the interview transcripts of the non-verbal interactions between partners, tone, pauses, laughter, and crying in addition to the verbal content. These notes were an integral part of the narrative analysis.

Narrative Analysis

After the interviews were transcribed, I analyzed them using the *holistic content method* and *categorical content method* as described by Lieblich, Tuval-Mashiach, and Zilber's (1998) in *Narrative Research: Reading, Analysis, and Interpretation*.

Holistic Content Method

Initially, I read and reread the interviews to analyze the content that was embedded within a larger context. The holistic content method helped me in presenting the interview material in narrative form and in attending to the entire story; whereas the categorical content method alerted me to the details and themes of each story. I read the interviews for the overall meaning of the stories, the elements that “spoke to me” (Lieblich, Tuval-Mashiach, & Zilber, 1998). I then wrote a brief overview of each interview in chronological order.

Categorical Content Method

After doing the holistic content method that illuminated the content of the story, I broke the stories down into small categories in order to interpret the most salient aspects of the content. Two categories were posttraumatic growth (PTG) and meaning-making since I was interested in determining if the inclusion of meaning-making and/or PTG in the participants' stories had some relation to them remaining together as a couple. Tedeschi and Calhoun (2004) conceptualize PTG as an experience of positive change that is a consequence of coping with an extremely challenging life crisis. Generally, PTG is manifested in “an increased appreciation for life, more meaningful interpersonal relationships, an increased sense of personal strength, changed priorities, and a richer existential and spiritual life” (Tedeschi & Calhoun, p. 1). To guide me in my search for meaning-making in the narratives of each couple, I kept in mind Reiss's (Reiss, as cited in Nadeau, 1998) notion of family

meanings which is that family members do develop shared constructs and one can see in the family's interaction how they respond to challenges and construe meanings interactively. I examined the content of the interviews for expressions of PTG and meaning construction through the couples' narrations and actions. Lieblich, Tuval-Mashiach, and Zilber (1998) discuss organizing the categorical content in 4 steps: (1) choosing a subtext, (2) defining content categories, (3) placing the material into the categories, and (4) making conclusions based on the results. I reread the transcripts many times while engaging in the data sorting process. Finally, using my findings from the categorical content analysis and the holistic content analysis, I revisited the original research question and determined if the data selected was representative of the interview data. I kept front and center the research question and only responded to data that was pertinent.

Representation

Chase (2005) describes how narrative researchers perceive themselves as narrators as they assemble interpretations and create ways to present the ideas flowing from the narratives they have heard. It felt most natural to me to represent the stories co-constructed by the couples and myself as holistic stories—with beginnings, middles, and endings. In Chapter Four, these stories are presented along with my narrative, the last story, which includes the themes across all of the couples' stories. The narratives stand alone as teaching tools. The researcher's narrative provides the reader with the authorial narrative lens.

Ethical Issues

In a study such as this potentially sensitive issues could have surfaced and safeguards had to be built in. As Rosenblatt (1995) passionately writes, bereaved people can gain tremendously from talking with someone who takes their stories seriously, and that experiencing grief in an interview is not necessarily a bad thing. Ethically, though, as a researcher, I needed to ensure that I was not causing the participants harm by focusing on painful matters (Rosenblatt). The informed consent documents included a warning that strong emotions might be aroused during or after the interviews, and that the interviews could be discontinued at any point. Secondly, I only selected respondents who had been bereaved at least 1 year, making the assumption that they were most vulnerable prior to that. However, I decided that if anyone seemed to be experiencing intense grief reactions during the interview, the interview would be abbreviated and I would refer the person or people to counselling services. Indeed, all participants were given information about counselling services in case the interviews brought up feelings that needed to be processed.

Another warning was made in the consent form that although it may be therapeutic for some participants to tell their stories, the purpose of the interview was research-related. However, even though it was not counselling, I think that as a researcher talking to people about their stories of child loss and grief, it is critical to use the counselling skills of listening, validating, being non-judgmental, and being supportive.

When reporting the data, I maintained the confidentiality of the participants by using pseudonyms. If there were aspects of the stories that participants requested I omitted, and I honored these requests. Additionally, narrative research, as Gilbert (2002) emphasizes, has a unique ethical issue which is about ownership of the story. Since narratives created in

research settings are co-constructed by the researcher and participants, problems may arise if a participant feels that their story is not represented accurately (Gilbert). I understood that I had a responsibility to avoid altering the stories in any way. To insure accuracy, I presented my interpretations to the couples to have them verify and give critical feedback before I made the stories public. Finally, participants were assured that all data will be destroyed five years after it is collected.

Lastly, to be an ethical researcher, I have made known any shortcomings of this study to my colleagues and in my presentation(s).

Criteria for Trustworthiness

Reissmann (1993) outlines three criteria used to judge the trustworthiness of a narrative inquiry: (1) correspondence, (2) coherence, and (3) pragmatic usefulness. I used these three criteria to establish rigor as well as the criteria of confirmability which is suggested by Siegle (n.d.).

Correspondence

Correspondence is also referred to as member checks and relates to the degree to which the findings adequately represent the storied lives of the participants. To ensure correspondence, I sent the transcripts and couples' stories back to each participant and asked them if they see themselves in the narratives and if the narratives adequately represent their experiences. They were given an opportunity to request that data be omitted, corrected, or added. None of the participants requested for data to be omitted or corrected. One couple asked that I add, with emphasis, how critical Canuck Place was in giving them a sense of being supported.

Another aspect of correspondence is linking the research literature on the topic to the findings. After analyzing the data, I spent time reviewing the relevant literature and looking for correspondence with my findings.

Feedback

All five couples shared with me that it was helpful for them to share their story with a sensitive, interested listener. One female participant shared with me that their final written narrative was something tangible that they could hold onto; it was a gift.

Coherence

Coherence refers to the extent to which the thick description reflects the overall objective the narrator is trying to accomplish in story-telling (Reissmann, 1993). It also relates to how clear the study is and if the findings are understandable. Presenting the stories to the participants aided in ensuring that the findings were portrayed coherently. In addition, I had my research supervisor and committee review the stories and provide feedback on clarity of the narratives. This sharing of perceptions, insights, and analyses also allowed for further understanding and served to give visibility to any potential researcher blind-spots.

Pragmatic Usefulness

I collected detailed, rich descriptions from my participants and reported this data sufficiently and with accuracy. To determine if my findings could be applied to other contexts or with other people, I showed my findings to two counsellors who work in pediatric palliative care and one bereavement counsellor. These counsellors reported that the findings were useful and have pragmatic value to counsellors and educators working in the field of palliative care and grief and loss.

Confirmability

To show that the findings are the product of a focused inquiry and not influenced by my biases, I reviewed the audiotapes and transcriptions; my process notes in my journal; notes that include any hypotheses or assumptions I had about the data; and the final narratives that I wrote using reflexivity.

Researcher's Subjectivity

When I heard the news, this world changed for me. It no longer felt like I was being enveloped by warmth, protected from the pains and challenges that living beings must face at some point in our journey. I felt exposed, naked in a frigid environment and uncertain of what direction to take to find somewhere that would alleviate the shivering in my body and the dullness in my brain. I didn't want out, *per se*, I knew I needed to accept the news and adapt to this new reality. I couldn't find refuge in my previous idealistic way of viewing things because I was being taught at that moment that being idealistic doesn't prepare you for harsh realities. I couldn't trust idealism anymore. It had deceived me. It had scammed me. It had sold a portrait of life to me that was inaccurate. *(From a journal entry I wrote in January, 2003)*

In 2000, I lost my older sister after she died in a hiking accident. For about 1.5 years after my sister's death, I perceived myself as being absolutely shattered. That was my self-image. I would shift back and forth between numbness and being too conscious of what had happened to my family and myself. I spent a year and a half wearing sweatpants and barely making it out of the house aside from attending some of my university classes. Slowly, though, after more time had passed, I realized that although I was living a new existence, a less "happy-go-lucky" one, it didn't sit well with me to give up on life. Indeed, I heard my deceased sister urging me to live it up and not remain defeated by despair. I recall my mom saying to me one day about two years after Lynn died, while I was deep in depression, barely able to make it out to my university classes, "You either sink or swim, Niki. It's your choice." With trepidation and a slice of resistance, I chose that day to swim and continue

swimming. I also realized that in this new world, I would have to spend my time doing things that energized me, gave me hope, and kept me connected to others.

In the last number of years, the word grief, for me, has represented two distinct parts of my life and my self. One of my identities has been as a researcher/student and at the centre of my studies are the concepts grief and loss. More deeply connected to me, though, is my identity as a bereaved sibling and because of that, grief is a very personal and sensitive topic. In the process of designing this study, it became clear that these two identities or roles are really not so separate but, in fact, are inextricably linked at times. They work as partners, informing one another. It is almost like the romantic partners in this research project—they have their individual experiences and then there are parts of their processes that are shared.

As a researcher, I have felt compelled to search for answers to these questions: how do grieving people live in a society that traditionally and chronically avoids/denies the thoughts and emotions provoked by grief and loss? How do their relationships with family members and friends enable their necessary grieving or challenge it? How do parents survive after the death of their child due to an illness, when despite all of their love and protection they ultimately did not have the power to prevent their child's demise? As a survivor of a loved one's death, I sought out methods to help me not only exist but thrive despite the painful tragedy. Interestingly, it has been learning how *other* people exist/thrive in the throes of grief that has given me some of the energy I have needed to keep living. In essence, it has been that sense of contribution, connection, community, understanding self and others, that has replenished and reinvigorated me along my journey.

I entered the process of my study with a feeling of urgency to give voice to parents who have survived a child's death. I am motivated by my parents' relationship that has

strengthened during their intrapersonal and interpersonal bereavement journeys. They have shared with me anecdotes about friends who have also lost children and have kept their marriages together and full of love. As a worker on the pediatric cancer ward at British Columbia Children's Hospital (BCCH), I have been witness to married partners/couples who have held onto each other through the stages of their child's diagnosis, treatment, palliative care, and into bereavement. I want to be transparent about my background as I know that it served as both a resource and a possible source of bias in the data collection and analysis phases of my study. I have included a brief description of my personal experience so that the reader will be able to understand my interpretive stance. As Chase (2005) explains in her discussion of narrative research, it is crucial for the researcher to treat participants as subjects, rather than objects, *and* to also consider their subjectivity. This is the lens that I viewed the narratives from and it did influence my analysis. I used caution and reflexivity so that the narratives speak for my participants and not for me.

CHAPTER FOUR

Stories and Themes

There are big and small stories behind all that we know. It has never been sufficient for me to tell someone I care about that my sister died and to not tell them stories about her and our relationship. It is my way of not losing her; keeping her alive in my memory and others'. Likewise, it has never been enough to read or hear that someone lost a loved one and to move on to the next event without stopping and asking them to share, if they'd like to, about that person. In this chapter, I hope to honor the experiences of the couples I interviewed by sharing the stories that uncover the experience of having a sick child who died. This is a way of helping them honor their child.

Without the willingness and openness of my participants, this chapter would be devoid of richness. I was fortunate to have 5 couples who sat with me and let me into their worlds of coping with a severely sick child and managing the grief that has accompanied those children's deaths. As my friend Elaine Stevens would say, I got to be in the presence of the "nakedness of the human spirit" which was a real privilege.

Co-constructing Stories

Each couple generously welcomed me to participate in the conversations and, so, instead of feeling like an outsider or a clinical researcher, I felt 'part of' the research process. In describing the collaborative nature of their research methods interviewing bereaved parents, Riches and Dawson (2002), use the term 'exploration' as opposed to 'observation' to reflect how they interacted with their participants. As I sat in the homes of 4 of the couples, and in an intimate room in Canuck Place with 1 couple, it felt like each had let me become an explorer of their experiences with them. These couples did not answer any of my questions

in a sentence or two, they told stories abundant in details and emotions. During the time I spent reflecting on the interviews, I rediscovered the reason why I cared so passionately about doing this particular research: Because grief always occurs in the context of relationships (with self and others) and that once you are in grief, evidently, you can never go back to life without it. And that, to me, should be known by people.

Chase (2005) extensively argues that how the researcher listens to the narrators' voices both during and after an interview—while writing and reading the transcripts—is the *researcher's* voice and I agree with this. Thus, during the process of reading and re-reading the complex and multi-dimensional interview transcripts as well as my reflection journal, I made a concerted effort to separate my voice from the participants' voices so that I could be open to what the narrators were trying to communicate to me through their stories without being blinded. I understood the tentative nature of my findings and happily relied on the participants' feedback of the drafts of the narratives to inform me about the stories' accuracy, or lack of. Ultimately, these were co-constructed stories.

To honor the tradition of narrative research, which tends to move away from using theme-oriented methods to analyze qualitative data, I chose to present each couple's story as a holistic story (Chase, 2005). Notwithstanding, though, I believe that locating the themes across interviews to be of practical and theoretical importance. To do this, I intuit that it is beneficial to list experiences that the bereaved couples in my study had in common. I discussed the themes across couples following the couples' stories. To orient the reader, I introduce each couple before telling their story. Pseudonyms were used to protect the privacy of the individuals who participated.

Following, are the couples' stories.

CHRISTINE AND DON

Christine had contacted me about the study after receiving the letter of invitation. We talked briefly about Michael and her experiences at Canuck Place and in bereavement prior to the interview in this phone call. She said that she was happy to help out and they looked forward to sharing their story with me. I met with her and Don about two weeks later. I conducted the interview at Canuck Place in the music therapy room. The interview was about 1.5 hours in length.

It was an energizing meeting with Christine and Don. There was an aliveness about them that was enjoyable to be around. They both had a lot to share and were happy to have a listener. They are both in their early thirties. Don works in the health industry and Christine recently went back to school to become an accountant. Don and Christine have a son in addition to their deceased son. While telling their story, it was interesting to observe the couple processes; they allowed each other the space and time to talk about their individual bits and there was overlapping and, at times, excited voices when they were discussing couple experiences. Overall, they were very comfortable story-telling together and seemed comfortable to have me there listening.

Two Souls Against the World

Looking back on their relationship, after nearly a decade of being married, Christine and Don recognize that they have always been best friends. While their relationship has remained stable, what they have been through together has not been predictable or easy, to say the least. On July 11, 2003, Christine gave birth to their second child, a boy named Michael. They had hopes that this child would be healthy and not have any physical or developmental challenges unlike their other son John who has apraxia. They were also very excited about giving John a sibling. Michael was a wonderful baby. He seemed to be developing normally and nothing indicated that he wasn't healthy. However, the picture started to change dramatically around Christmastime of that year when he was about 5 months old. Christine and Don noticed that Michael couldn't hold his head up, he would arch his back and his arms would stiffen up, and he didn't have very good muscle tone. Around that time, he also had a bout of chicken pox which really took a toll on his system.

The couple braced themselves because they knew that something with Michael was seriously wrong even though they didn't know what it could be. After going to their pediatrician and having tests done, the doctor told Christine and Don it could be cerebral palsy. Since Don's sister has cerebral palsy, they had a good understanding of the disorder. The couple started preparing themselves for that diagnosis and what life would be like if Michael did, in fact, have cerebral palsy. They had no idea that the real diagnosis would be much worse.

Almost immediately after their visit with the pediatrician, Michael started having respiratory distress and after a maddening night at two different hospitals, Christine and Don learned that Michael had mitochondrial disease. Although they had been planning for the

struggles that arise caring for a child with cerebral palsy, Don and Christine now had to confront a life-limiting diagnosis and the news that their child would eventually die from the illness he had. So rapidly, life became very different for these parents. Like all young parents in the early stages of life with a new child, they had hopes and dreams and now had to concede to a bleak reality and shift gears.

With the diagnosis that Michael had it was unpredictable what the illness trajectory would be; it was unknowable if he would have periods of stability and live for years or would be acutely sick and die young. Grief entered the scene early for Don and Christine. Don recalls his worst grief point, “the darkest night of the soul,” being shortly after the day they received Michael’s diagnosis. For both Don and Christine, the grief wasn’t just about the loss of their personal dreams but came from placing themselves in Michael’s shoes and feeling bad for him. Don and Christine engaged in lots of conversations about Michael, his illness, and their feelings. They felt like “two souls against the world.” One thing that they were unequivocally in agreement about was what they would do if Michael progressed to a place of being in extreme discomfort—that they would want to let him go, let nature take its course. Indeed, Don and Christine rarely disagreed about anything and were able to support each other throughout the difficult journey. They naturally fell into certain roles, with Christine being the primary caregiver—spending lots of time at the hospital with Michael—and Don looking after John.

The family spent quite a bit of time in and out of Canuck Place, a children’s hospice in Vancouver, in addition to British Columbia Children’s Hospital. Michael frequently needed medical attention and thus it was rare that Christine and Don could take any time away to be just with each other. Friends and family would often encourage the couple to go

on a date and when they followed the advice they would find themselves spending the entire date talking about Michael. Unsurprisingly, that is where their minds and hearts were.

Around June 2004, it became clear that it was just a matter of time before Michael died as his health was getting increasingly worse and he had stopped eating. The family had plans to throw Michael a party for his 1st birthday at home but instead they celebrated at Canuck Place. Michael died on July 30, 2004.

As they travel the path of bereavement, Don and Christine acknowledge that they are “wounded people.” Christine, with passionate honesty, describes how losing their child has destroyed every part of their life; that everything has suffered, and that *they* are *suffering*. Fortunately, they have walked into this new world together—a world where they are acutely aware of death and grief—and their relationship is as strong as it was before this trauma. Although their interpersonal relationship hasn’t transformed much, who they are as individuals has and it is as though they are constantly getting to know different people. Both Christine and Don left their very social selves behind and have become more withdrawn around others. They used to get a lot of energy, as a couple, being around a lot of people. That is not the case anymore.

Their status as bereaved parents has become central to Christine and Don’s identities. Christine says that “maybe we’re more compassionate now” but qualifies that by noting that they were pretty compassionate before. What has certainly changed is who they are in their social lives. They each have parallel stories of being in social situations where they couldn’t handle being around the other people for too long. Christine recalls going to a Christmas party the year that Michael died and feeling miserable. Don talks about being so conscious of the difference between his life and those of his work peers, many of whom had children at

the same time that they had Michael, that he would just want to “show his face and do the corporate thing” and then leave quickly from company parties.

Bereavement is such a large part of the couple’s life that their closest friends now are all people who are bereaved. These are people who can understand that Christine and Don don’t want to put on a front of being “bravely bereaved” or happier than they actually are. With these friends they can talk openly about Michael without feeling uncomfortable bringing him up. Unlike others in their lives, these friends who are part of the bereaved club understand that there isn’t a timeline for grief and Christine and Don can’t be hurried through it. The safe, supportive space of Canuck Place’s bereavement group has also played an enormously helpful role in comforting not only Christine and Don, but assisting John with his coping as well.

Losing their child has had a powerful impact on the couple’s way of being in the world. One method they used to attempt to soothe themselves or escape the pain of their grief was to spend money freely (and, at times, carelessly)—something that they never did prior to Michael’s death. It was also a result of having a new perspective on life. They both see life as more fragile now, that it is short and some things they used to see as important are now viewed as trivial. They have had to accept that bad things do happen and that things they plan for—have two sons close in age, together forever—do not always work out. Their biggest focus now is on providing as much affection and love for John as they can.

Even though Michael is not alive anymore he still is an important member of the family. The absence of his physical presence is deeply felt though. Recently, the family was on a long drive and a song came on the radio that John loves. They all were singing and Christine suddenly broke out into tears. Here they were as a family sharing a happy moment

but during that moment the missing of Michael became so pronounced. Don completely understood what was happening with Christine without her having to explain. They both talk about how it is hard to have “guilt-free fun” or “whole fun” now. Thankfully, they understand what is going on for each other and allow their partner to have the space and time to be in their emotions. They are there to offer each other support. They are nurturing with each other and neither are “hostile people.”

Although not much has changed in their relationship with each other, one notable difference has been in the area of intimacy. Christine has found that she has needed to be quite self-soothing and “insular” since Michael’s death. She has preferred to not be too physical with Don and has needed her space. Don has a different coping style and has been more comfortable with being physical close and wanting intimacy. However, for both of them a challenge while Michael was sick was having the space and time to physically connect with each other. It was rare for them to not have nurses or other family members around.

Difficulties with intimacy for the couple also speak to the meaning or purpose assigned to sexual intercourse. They want to have another child but are uncertain about how they will go about doing this considering that Michael died from a genetic disease. The couple has decided that they will defer talking about this and making decisions for a number of years. For the time being, they will concentrate on settling into life, loving John, and Christine has recently gone back to school so she will be busy with that. They are also working on rediscovering the passion they have for each other. Now they are interested in discovering the reasons why they are married to each other again.

Don and Christine, the two souls against the rest of the world, move forward holding each other's hands and the hands of John. And Michael will always be with them as they deal with life's ups and downs. Although they have been damaged by life's circumstances, they do have each other and they have a network of people in their lives who understand what it is like to be in the world of grief.

JACK AND LINDSAY

Lindsay telephoned me about the study after receiving the letter of invitation and said that she and Jack would like to participate. I got a few details on the phone from her about Jamie and then met with her and Jack about a week after the first phone call. The interview was conducted in their home. The interview was about 1.5 hours in length.

Being in the room with Jack and Lindsay as they opened up about their experiences was powerful. Emotions were close to the surface for them and I found that I was deeply moved by what they shared with me and also by how they were sharing it. Jack is in his early forties and Lindsay in her late thirties. Jack is a business-owner while Lindsay takes care of the home and their children. They have two young daughters in addition to their deceased son. In the interview, like with the other couples, it was special to observe their couple processes. Jack gave Lindsay as much room and time as she needed to reveal her thoughts and feelings and her experience of the events they lived, and Lindsay did the same for him, although he didn't talk as much as she did.

Hope Will Keep Us Alive

Lindsay and Jack were an inseparable and adventurous duo before deciding to settle down and have their first child. In October 1998, after more than a decade of being together, Lindsay gave birth to Jamie. The couple had always enjoyed doing projects together and this new project—caring for their Jamie—was going to be unlike anything else they had ever done and probably ever could conceive of doing. In March 2001, Lindsay and Jack welcomed their second child, a baby girl named Dawn, into the world. Jamie, who was 2.5 years old at the time, was having headaches and difficulty balancing convincing Lindsay and Jack to consult with their pediatrician. Although they were worried about Jamie, nothing could have prepared them for the news they got 10 days after Dawn’s birth day: Jamie had cancer and they were going to operate on his brain the next day.

The couple, who describe themselves as “positive” people, plunged right into the world of care-giving for a child with cancer with their heads up and their minds’ optimistic. Never asking “Why us?” Lindsay and Jack, with the help of, primarily, Lindsay’s mother and Jack’s sister, joined together to make this a team effort. Jack, the owner of his own company, was able to excuse himself from work and engage with Lindsay and Jamie as they moved through treatments, appointments, and hospital stays. The family lived in a bubble during the three years of Jamie’s sickness and friendships weren’t part of their life during this time. During that period of time, Jamie, oblivious to the fact that he had cancer, embraced life with his family and was a happy child, fortunately suffering little from the side effects of chemotherapy or any complications to do with the illness or treatments. It was easy for Lindsay and Jack to find meaning during that time, especially because Jamie was such a powerful presence.

Unsurprisingly, due to the nature of having a child with a cancer that comes with a 30% chance of survival, these were also very emotionally and psychologically stressful years for Lindsay and Jack. Lindsay, someone who copes with her emotions by “letting it all out,” felt blessed to share her feelings and worries with her mother. Jack, on the other hand, was less available to have emotional conversations with as he is an individual who prefers to keep his feelings inside. He also was working hard to remain hopeful that Jamie would survive and resisted any ideas that countered that belief. Jack and Lindsay’s hope and belief that Jamie would live was central to their parenting. This hope allowed them to stay positive and focused, giving them strength as individuals and as a couple. Indeed, they never let go of hope until the day that Jamie died.

On Halloween day in 2003, their doctor at British Columbia Children’s Hospital told Jamie’s parents that nothing more could be done. Jamie’s cancer had gone into remission a couple of times, but with this relapse the cancer had spread into his spine. Jack and Lindsay were told that efforts would now be made to manage Jamie’s pain effectively but that active treatments to cure the cancer would no longer be offered. For the most part, the couple got along well enduring the ups and downs of Jamie’s sickness, but they had some difficult conversations around decision-making. For instance, Lindsay, more open to alternative medicine and willing to take the risks that come along with some of those options, was interested in exploring a cancer clinic in Texas. Jack was skeptical about this particular clinic but, respecting Lindsay’s opinion and interests, was willing to research this possibility. Ultimately, he decided that it was too big of a risk and so the family stayed put. Despite having opposing perspectives on alternative therapies, Lindsay and Jack always agreed upon

insuring that Jamie was in high spirits. Within reason, they also clearly wanted to do whatever they could to keep him alive.

It is impossible to emphasize enough how important the role hope played in their lives. Even though the doctors told the couple that the focus would be pain management now, and not curative treatment, and they encouraged Lindsay and Jack to go to Canuck Place, a Vancouver children's hospice, the inevitability of Jamie's demise was not that apparent to them. They were not paying conscious attention to the signs that death was near. Jamie had two stays at Canuck Place. There was a brief visit shortly after that Halloween appointment and again for about a month over December. In January, Jack and Lindsay took Jamie home and took care of him there, with minimal help from home care nurses, until March 2004. On March 1 at 9 in the morning, Jamie, lying in Jack and Lindsay's bed, where he slept with them, told his mom, "Mommy, I love you" and then he closed his eyes and peacefully, quietly died. They didn't expect that he would die that day. Even their doctor, who had visited Jamie that morning at 8am, believed that he had more time. But it couldn't have happened in a better way with both Jack and Lindsay there with him and with each other to share in Jamie's last moments alive.

It has now been over two years since Jamie died but his presence is strongly felt by the whole family, including Dawn who talks about her deceased brother. Although when Jamie was diagnosed with cancer life became very different and required Lindsay and Jack to make adjustments, it has been his death that has resulted in a need for major adaptations for the couple. Since Jamie's death, their relationship has encountered more stress than it did during his illness. Both Lindsay and Jack think that their relationship was strong prior to Jamie's sickness, during it, and believe it is just as robust now but they acknowledge that

they have been dealing with certain difficulties since their son died. For instance, Lindsay benefited greatly from having her mom around during the years of Jamie's illness; she served as an outlet for all of Lindsay's emotions and now Jack is the one she expresses her feelings to. She is aware that her emotional needs have changed since Jamie's illness and death, that she needs more emotional intimacy and accessibility with Jack.

The couple is making slow progress in learning how to communicate with each other in a way that is satisfying and comfortable for both of them. Jack believes that he might be more of an optimistic person than Lindsay and that what they choose to discuss might be a reflection of this. One topic that is always very easy for them to talk about, though, is Jamie.

This process of bereavement has been filled with a need to reevaluate their individual, couple, and family goals. Tension has emerged in Lindsay and Jack's relationship because Jack is very consumed with work, something that was not true when Jamie was sick and they were caring for him. Because he is in charge of the company, Jack finds that his work demands a lot of time and energy and that it is challenging not to bring it home with him. Lindsay reminisces about the years when Jack was more available to participate in family life. Jack has a lot more going on external to family life compared to Lindsay. In addition to work, his schedule includes regular hockey team practices and games. This has had an impact on Lindsay: She misses what family life was like when Jamie was still alive and they were all always together and she also recognizes that she needs to find fulfilling activities to engage in like Jack has so that she doesn't resent him. Jack emphasizes that it puts more pressure on the partnership when neither, or only one, partner, has many outside sources they can use for support.

This has been a period of reflection. Lindsay notices that it was easier for her to have access to the “truths” or “lessons” of life when they were in the midst of Jamie’s illness. Jack and Lindsay realize that shortly after Jamie’s death it was more effortless to not get ruffled by trivial issues and they felt inspired to live life differently, more conscious of the important things. Yet after awhile they both found themselves back in day to day life getting wrapped up in little things again. Lindsay feels like she was more inspired back then to create and find meaning and purpose and now her goal is to get back into that headspace.

Jack and Lindsay have been together for 21 years and they are still in love. They survived Jamie’s illness and death together, as a team, and are adapting to life without him. Although their relationship is encountering new stresses and challenges, as a consequence of these circumstances, they are characteristically up for the task. When they look back on their relationship and what they’ve been through together, it is clear that their partnership has evolved and *is* evolving and what’s in store for them in the future is not yet known. What *is* known is that they are just as close as they ever were and they are committed to honoring Jamie by living life the way he did: embracing it wholeheartedly with high spirits.

ANNIE AND RALPH

Ralph telephoned me about the study after receiving the letter of invitation. We talked a couple times on the phone before I met with him and Annie at their home. He shared a lot with me on the phone about his perceptions of Canuck Place, challenges in having a child with Duchenne's muscular dystrophy, and stated that he and Annie wanted to help other parents who are care-giving for a child with this disease.

The interview was about 1.5 hours. I was moved by Annie and Ralph as soon as I met them. They were immediately forthcoming with their story—launching right into it and not holding back. They were passionate and both allowed their emotions to surface. I enjoyed watching them interact with each other; a playful dynamic with a clear deep love and appreciation for one another. I was especially captivated by Ralph's affection towards Annie. Annie and Ralph are in their early 40s and Annie works with developmentally disabled individuals and Ralph is a truck driver.

We Are Each Other's World

Give Annie and Ralph a challenge and they're up for it—as long as they get to fight together. For this couple who began dating 21 years ago, life together has never been short of difficulties but as Annie states, “we could not have a pot to piss in or a window to throw it out of” and, Ralph, finishing Annie's sentence, “that would just give us a reason to fight harder.” Neither the type to take the back-seat in life, Annie and Ralph not only discussed having kids right off the bat, but put words into action. The couple welcomed Justin into their world on February 8, 1987 and Annie and Ralph got married in August 1988. Things did not slow down or get simpler then for the young family but, as feared, when Justin was two years old he was diagnosed with muscular dystrophy, a hereditary disease Annie knew all too well about as her brother, Lucas, suffered from it.

In addition to the full-time care-giving that muscular dystrophy calls for, Annie and Ralph were confronted with the knowledge that their son had a fatal condition that would get progressively worse and end in death likely during Justin's teenage years or early adulthood. Instead of dwelling on the devastating prognosis, Annie and Ralph focused on giving Justin a normal life and trekked on with the hope that he would exceed the expectations of the doctors and live longer than Lucas who died at 16. They also were determined to never let their son know the severity of his condition (a decision that proved to cause conflict with doctors).

Three years after Justin was born, along came Rachel and Annie and Ralph had two distinct roles and job descriptions both requiring an abundance of energy and time. Annie dedicated nearly 24 hours a day, 7 days a week to caring for Justin who, as time went on, needed more attention, procedures, and doctors' appointments. Ralph, making sure that the family could eat, was out on the road 6 days a week truck-driving. Although they often were

not physically in the same place, Annie and Ralph's minds were always on the same thing: Justin. Even though the parents wanted to have equal involvement with Rachel as they did with Justin, it was challenging to do so given his needs. Not being able to give Rachel more time and energy, as well as more normalcy in her life, induced guilt for both parents. At one point, Ralph and Annie even told Rachel that when Justin died it would be her turn.

Despite the occasional argument about Annie wishing that Ralph could be around more to help out, the couple drew strength from each other while coping with the stresses of having a disabled son. Annie and Ralph were each other's main sources of support. Indeed, Ralph was inspired by Annie. He was amazed by her commitment to Justin's care and acceptance of the circumstances; for instance, never asking Ralph to quit his job or anyone to help her out with Justin.

While Ralph considers himself the "coolheaded one," Annie dealt with the emotions that accompanied Justin's condition by yelling at people and releasing her negative feelings that way. Fortunately, friends and family understood not to take her outbursts personally and Annie's "bullheadedness," her tough attitude, is what kept her going. In bed at night, though, the mother, the caregiver, the wife was able to break down and cry sometimes in the loving arms of Ralph. Justin had attitude too; a perfectionist like his mother, he was someone who liked to be in control and lived life full throttle, not wanting anyone to get in his way, from the moment he woke up in the morning until bedtime.

Having been the sibling of someone who lived with muscular dystrophy and died from it, Annie was acutely aware of what would happen with Justin and of the pain associated with loving and losing someone with the disease. Even though both Annie and Ralph knew that Justin ultimately would not survive and defeat the disease, they rarely

discussed that reality. Instead, their conversations—typically had over coffee when both of their children were in bed—were about problem-solving and what their plan of attack would be if certain things happened. How Annie’s parents dealt with Lucas’s muscular dystrophy and Lucas’s responses to treatments provided examples for what Annie and Ralph would want to do but more often did *not* want to do in taking care of Justin. They positioned themselves as advocates for not only their son but other children with muscular dystrophy and Ralph and Annie were always in agreement about the small and big decisions with respect to Justin’s treatment, including, especially, that Justin would die at home.

As is the case with children who have muscular dystrophy, by the age of 10, Justin’s entire body was getting weaker and weaker. When Justin was 11 years old, he nearly died at the hospital. His heart had stopped beating and the doctors revived him. It was at that moment that Annie realized that her dream for her son to live forever, or at least a long life, was not realistic. Ralph and Annie asked Justin shortly after this traumatic experience at the hospital if he would want to be resuscitated if anything were to ever happen to him in the future. His answer was a definite “no.”

In 2000, Ralph and Annie were told by Justin’s doctor that their son likely had about 6 months left. In spite of that information, Ralph and Annie still believed that their son would live at least as long, if not longer, than Annie’s brother who died at 16. Perhaps denial was playing a role here too; disbelief that their vibrant son would succumb so quickly to his disease. Yet on September 10, 2001, at age 14, Justin passed away at home with both his parents by his side.

For Annie, losing Justin, was saying goodbye to the person she was for 14 years; to the routines and to the emotions that came with being his mother, caregiver, advocate. Her

day to day life dramatically changed whereas Ralph's did not, thus creating some resentment on Annie's part. While Annie's grief is always there with her, she is also appreciating how normal life is now. With a sliver of guilt, she acknowledges how much she enjoys being able to sleep the whole night now—something that was impossible during Justin's life. Still there is continuity in how Annie's life was when Justin was still alive and how it is now because she has chosen to work with developmentally disabled individuals.

Annie's sense of loss has been greater; although, with that said, Annie and Ralph's grief is equally tremendous and painful and not a day goes by without Ralph thinking of Justin. Indeed, the bond that each Ralph and Annie continue to have with their son binds *them*. Ralph's awe of his wife and her strength persists and he says with passion that if he had to do this all over again he would as long as Annie was by his side. He says that "she is his world." They are in agreement that they have definitely grown as a couple after going through caring for Justin and being bereaved by his death. As Annie says, "they are still in the honeymoon stage" in the sense that, as a couple, they keep encountering new challenges and chances to prove their capacity to shine together. Perhaps it is Justin's energy and love for life that continues to push them to live fully and wholeheartedly.

GAIL AND ANDREW

Gail e-mailed me after receiving the letter of invitation for the project and said that it had been on her and Andrew's pile of things to do and that they would be delighted to talk about their experiences in palliative care and bereavement after losing their daughter 9 years prior at Canuck Place. She wrote that her and Andrew would be happy to have me over to their home.

I interviewed the couple at their home and was impressed by both of their self-awareness and insightfulness. The interview was about 1.5 hours. There was a cute chemistry between the two of them that spoke to their love and also, I thought, to their comfort with each other after over twenty years of marriage and living through many big experiences together. I heard many stories during that interview and was moved by the content and the dance I saw between Gail and Andrew as they told these stories.

Gail and Andrew are both in their early forties. Andrew works for a telephone company and Gail works in an administrative role at a hospital.

Bonded by a Common Faith, a Common Love

Gail and Andrew came of age together. Both growing up in small towns, they married when she was 19 and he 20 and from there they moved from one remote community to another for Andrew's work until they finally relocated to a big city. They were a happy couple who liked to do similar things and were also deeply united by their common faith—they are both Jehovah's Witnesses. In 1989, after nearly 6 years of marriage, Gail, unexpectedly, got pregnant and on June 20, 1989, Elizabeth came into their lives. Andrew had thought that he would have "preferred a sports car" but the reality was that when he and Gail became parents, he realized how much he loved children. In the beginning of Elizabeth's life, neither parent had any idea what was in store for them.

When Elizabeth was 8 months old, Gail began noticing that something was wrong with their daughter. There was nothing "specific" but she would just watch her daughter play or interact with her and something told Gail that Elizabeth wasn't developing the way a normal baby would. It was a gut feeling and Gail also found herself comparing Elizabeth to their friend's daughter who was 4 months younger and seemed miles ahead. Being a concerned mom, Gail took Elizabeth to the doctor and he said not to worry and she was just being a typical anxious mom. Yet when Elizabeth was two, she started having seizures and shortly after Elizabeth's sister, Naomi, was born in December 1992 she went from having 10 seizures a day to a hundred. It wasn't long until she was having thousands of seizures each day. At that point, the family moved into children's hospital for 6 months to have Elizabeth tested. After a couple years of not knowing, when Elizabeth was 4, Andrew and Gail were delivered the news. Gail was leaving the hospital with Elizabeth and Naomi after Naomi had some dental work and their doctor came running towards her excitedly saying, "We just got

the results back and she has a progressive neurological disease and someone will call you.” Gail somehow made it home and after conveying the news to Andrew, the two of them sat around in shock. They weren’t sure then what that diagnosis meant.

Andrew and Gail were even more flummoxed when they heard the more specific diagnosis for Elizabeth: Neuronal Ceroid Lipofuscinoses, also known as Batten Disease. The diagnosis that Gail feared. The accompanying prognosis was that Elizabeth would not survive this; her parents knew that at some point it would be just them and Naomi. Shortly after receiving the diagnosis, the family was in the hospital for a few months—a period that was like a black hole, a blur for Gail. It was during this time that Andrew and Gail became “ships passing in the night” in multiple ways. Gail did the bulk of the care-giving at the hospital while Andrew worked and they mostly connected by frequent telephone calls. They were also on opposite schedules with sleeping and eating which made it difficult for them to connect as a couple. Andrew recalls one date in the years of Elizabeth’s life where they were able to not discuss their daughters for 10 minutes and that was impressive to them. Not only were they often physically not in the same place, Andrew and Gail grieved in different ways and separately.

Gail, having been through grief associated with her mom getting diagnosed with a life-threatening illness a number of years prior, knew that she needed to cope with her grief alone. She would wake up in the middle of the night, go into the basement and bawl. It was natural for Gail to do a lot of this anticipatory grieving for Elizabeth; often the emotions she was experiencing were expressed by journaling. Initially, Andrew’s different way of responding to the stresses and loss associated with their daughter’s illness provoked Gail. Andrew had a tendency to sleep a lot and used work as an escape. However, when Gail took

a course at the hospital for parents coping with chronically ill children she was able to recognize and accept that Andrew and her dealt with their emotions differently. Both were able to accommodate the other's style from there on.

Despite acknowledging and processing their sense of loss over what they knew would be a challenging and short life for Elizabeth, both Andrew and Gail took a long time to fully accept that their daughter would die from her illness. Perhaps it was easy, on some levels, to ignore or deny the inevitable because Elizabeth had good quality of life for years and the parents were dealing with present concerns. They were both so involved in actively caring for her and Naomi and interacting and receiving support from a large team of health professionals and friends. A significant portion of emotional assistance also came from their spiritual family who Gail, Andrew, and Naomi had meetings with three times a week. Indeed, this external support was like a blanket for the couple and family: protecting them and helping them along. For instance, Elizabeth's therapist made sure to inquire about how Gail and Andrew were doing and what they needed; a nurse, who they affectionately call Mrs. Doubtfire, was there offering comfort and a pair of ears to Andrew in the long nights spent at the hospital; and Elizabeth's preschool teacher came into their home 10 hours a week and helped work on the relationship between Elizabeth and Naomi.

In the fall of 1995, the family felt especially grateful because not only did they begin getting much-needed financial help from the government for home care but Canuck Place, the Vancouver children's hospice, opened its doors. Canuck Place became a home away from home. Many of the nurses were nurses from the ward Elizabeth was on at the hospital and the social worker had worked with the family before. From the time they stepped into Canuck Place they felt surrounded by love and caring—"a place like that becomes a home

very quickly.” Events around this time did thrust Gail and Andrew to admit to themselves and to each other that Elizabeth would be dying. There was the time that Elizabeth was at the hospital crying and when Gail asked her if she wanted to go home, Elizabeth smiled. Gail knew at that moment that she, as Elizabeth’s mother, had to respect that her daughter was saying “no more hospital.” Gail went home and told Andrew that they wouldn’t be returning to the hospital and would rely on Canuck Place’s respite and palliative care from thereon. The couple also were faced with the reality of their daughter’s death when they were required to sign a do not resuscitate order at Canuck Place when they began going there. The most profound foreshadowing event was in October 1996 when Elizabeth nearly died at Canuck Place and the nurse encouraged Gail and Andrew to make their calls.

Managing the practical and emotional issues surrounding caring for Elizabeth and preparing for her death was a family affair. Despite Naomi’s young age, Andrew and Gail involved her entirely in decision-making about her sister’s care. Decisions such as if there would be a viewing, if Elizabeth would be cremated or buried without cremation, if she would die at home or Canuck Place were made by having consensus amongst the three of them. The parents were not solely thinking about how they were coping and would adjust to life without Elizabeth but about how Naomi would be when it was just the three of them. Focusing on Naomi also helped normalize life for the couple. In November 1996, the three of them went away for a week to the island while Elizabeth stayed at Canuck Place in the care of a nurse. Gail and Andrew also remember weekends where they would leave Elizabeth at Canuck Place and would experience a multitude of emotions, including giddiness and excitement related to not having to tend to their daughter. These feelings were

usually followed by heart-wrenching guilt and the couple talked with each other about the mixed emotions and also to a therapist.

In the summer of 1997, it was clear to Naomi, Gail, and Andrew that Elizabeth was dying. When they drove to Canuck Place in early September, the parents had a strong sense that this would be their last drive there and Elizabeth would not be returning home. It was on September 21st, while Gail and Andrew were playing cards with two good friends of theirs in Elizabeth's room at Canuck Place that Elizabeth passed away while holding hands with her mom. It was late at night and the fact that Gail and Andrew were playing cards while their daughter died was significant as they were playing cards while they were waiting for Elizabeth to be born.

It has been 9 years since Elizabeth passed away and, as a couple, Gail and Andrew have encountered their share of challenges and also growth. Because Gail did a lot more anticipatory grieving than Andrew, they were in different places of grieving for a long time. The largest test of their relationship came shortly after the family returned from a summer's trip to Europe two years after Elizabeth died. Andrew was yearning for another child and Gail, although feeling similarly, strongly believed that it was not a good idea because of the 25% chance that this next child could inherit the disease Elizabeth died from. Gail also felt that their marriage would not survive another experience like what they had been through and Andrew did agree with that. Andrew became distant after this conversation and defaulted into sleeping a lot and being angry. It took 3 years until he revealed to his wife the impact that the conversation had on him. This was around the five year mark after Elizabeth's death. They survived these trying times by continuing to do things together as a couple and as a family. One significant thing they did was move houses which brought them geographically

closer to good friends. Re-connecting with friends and starting fresh in a new place helped Gail and Andrew begin to sort things out. Gail had promised Elizabeth that after five years, they would be okay and they are.

Even though they still have arguments with each other, Andrew and Gail believe they have become more patient and understanding with one another and that they have definitely grown together. Being members of their spiritual family and learning to speak sign language together shortly after their daughter's death has also assisted the couple in staying strong together by making meaning and keeping things new. Their belief that Elizabeth is "in God's memory" and one day will be resurrected back to earth, to a beautiful paradise, also keeps them moving along with positive thoughts. Watching and caring for outgoing Naomi also keeps their spirits up. This family has been through devastating times but have remained a united, solid team.

SUMEET AND RANA

Sumeet telephoned me after receiving the letter of invitation for the study and said that he and Rana would be honored to participate. In the 6 years since they lost their son, and during his illness, they have been involved with many people, including the media, telling their story. It was clear, on the telephone and while interviewing them, that there is a sense of urgency to continue their son's legacy.

I heard Rana and Sumeet's story at their home. The interview lasted 3 hours and involved watching two videotapes of their son that were shot while he was still alive. I felt like I had entered a different world while listening to this couple talk about their experiences. I was touched by the clear empathy they had for each other and my perception that they were survivors together.

Rana and Sumeet are in their forties and they are both on disability pension and not working. Sumeet had been an accountant and Rana had worked in a plastics factory.

We Have Each Other on This Island

In 1984, atop a mountain, Sumeet and Rana decided that they would spend their lives together. They had met a few years prior, through relatives, while Sumeet was visiting Canada from his homeland Zimbabwe. However, he wasn't ready for marriage then but did put her name in his "black book." When the timing was right, though, the couple married, lived in Zimbabwe for a year and then returned to British Columbia. Rana and Sumeet purchased a large house and their desire was to fill it with many children. Each had many siblings and they hoped to carry on this tradition with their own family. Unbeknownst to the couple, this dream would dissolve within a couple of years after their first child's birth.

Darren was born in 1991. He was a healthy, happy baby who was achieving all of the regular developmental milestones: walking, running, talking. Yet, when Darren was about 2.5 years old, strange signs, such as difficulty with walking, bumping into furniture, and falling, startled Sumeet and Rana and their child was soon admitted to British Columbia Children's Hospital (BCCH) for testing. They lived at the hospital for 6 weeks and Darren was put through an extensive battery of tests. Immediately, the doctors knew that it was a metabolic disorder because of certain signs, but it took an arduous process to determine which one. Week after week, Sumeet and Rana were hit with increasingly bad news about their son. At first, it was "Darren is going to lose his eye-sight," the next week it was, "Oh we're afraid he is not going to be able to walk," and finally, at the last meeting, "Your child's survival is going to be 12 months." Darren was diagnosed with a very rare metabolic disease called Multiple Sulfatase Deficiency. At the time, he was the only child in Canada with the illness and one of about a dozen in the world.

Rapid changes took place in Darren's health shortly after the diagnosis—as the doctors predicted. It felt like going down a slope fast for Sumeet and Rana: They were juggling the grief and anxiety which accompany having a dying child and going through the huge “learning curve” of caring for their son appropriately. In a span of only 3-4 months, their son required tube-feeding, became blind and was completely paralyzed, and, unfortunately, it was an understatement to say that support from health care professionals was inadequate, especially during the first two years. Darren's health issues were so all-encompassing—like putting out fires all the time, all over the place—that everything, including the couple's relationship and Rana and Sumeet's individual emotional/psychological difficulties, became secondary. All of their energy was spent trying to figure out what was happening to their dying child, the last thing they were worried about was “us.”

A visit with their family doctor soon after Darren's diagnosis, however, served to highlight that the couple relationship required attending to. Their doctor's advice was: “Whatever you do make sure that your wife and you can stay together because that's going to be the glue of this whole journey.” A psychologist at BCCH, who worked with them from diagnosis and throughout Darren's illness, also helped remind them of their individual and couple needs and to take care of themselves.

It was as though Darren, Sumeet, and Rana were inhabiting an island far away from normal reality. Shortly after Darren was diagnosed, Sumeet and Rana both made decisions to leave their jobs. Sumeet was an accountant and Rana worked at a plastics factory. They began relying on the little money that comes from disability pensions. Rana and Sumeet found that their views on life and what is meaningful began shifting as they travelled with

Darren on this journey. Their approach to living became simpler. Living essentially in isolation, their perspectives and priorities began changing. Comparing themselves to other couples they knew who were into fashion, going to the movies and concerned with material wealth, they found they were learning to survive by having less and simplifying. The couple discovered that they came to value dealing with the issues at hand and being efficient at their duties. They began recognizing new strengths, including “breaking out of their shells.” They both became more vocal about what they needed. One thing they needed, and expressed, was related to setting boundaries with other family members about how often they could visit. They also both became advocates for their child, and other children with special needs, in dealing with the Ministry of Children and Families.

The couple found that as they were coping with caring for their dying child, they took pleasure in connecting deeply with others who were walking similarly difficult paths. The parent support group at Canuck Place, the children’s hospice, offered the chance to commune with others who were living on similar “islands.” In fact, it was at Canuck Place where the couple realized that they were not bearing the “largest cross” and that other parents had even more burdens than them. The hospice also offered the couple continued support and care—anchoring during their journey.

Given the time and energy requirements of taking care of their son, Rana and Sumeet often did not have time for important conversations. Although they never explicitly spoke about it with each other, Sumeet and Rana had both embarked on a similar and profound spiritual journey while care-giving for their son. They derived energy for care-giving from their Hindu faith. At some point the focus for both of them changed from feeling burdened by caring for a dying child to seeing it as an opportunity to care for “God’s child.” They

never questioned, “Why us?” The couple viewed their son as a teacher and they were prepared to learn as much as possible about life and love as his students. One lesson was to always have a peaceful home. Darren could detect tension very easily and this pushed them to be peaceful with each other at all times in his presence. Indeed, a house rule that was enforced with anyone who came over, was to leave problems and negativity outside. Another lesson learned by the couple was figuring out how to communicate better with each other and become better listeners. This extended to Darren’s care: To look after Darren’s needs, Sumeet and Rana had to be able to pick up on subtleties in what he was communicating especially since he could not speak.

Despite what the doctors predicted, Darren survived much longer than a year. However, at the age of 10, on May 18, 2001, Darren died after a rough period where it was obvious that his health was deteriorating. With his mother and father by his side, Darren died on a Friday morning—triggering memories of his birth day which was a Friday as well. As planned, Rana was at his side, along with Sumeet. This was significant as it took Rana up until that week to accept the reality that Darren would die young. Eerily, she had dreamt prior to Darren’s diagnosis that he was going blind and wouldn’t live much longer. She realized it was God readying her for what reality was going to be; still, for a long time, the reality was nearly too much to bare. Sumeet accepted this eventuality shortly after Darren’s diagnosis and found that he was less emotionally labile than his wife.

Following Darren’s death, Rana and Sumeet commenced a new journey that has involved tremendous suffering and growth. There have been huge costs to every area of their lives and the 7.5 years of a “treadmill existence” during their child’s illness has made it impossible for either of them to go back to work and resulted in posttraumatic stress disorder

for both Rana and Sumeet. Similar to their existence while Darren was still alive, Sumeet and Rana still feel they are living in a “different world” and adjusting to normal life has been difficult. One factor that has made it especially challenging in adjusting to bereavement has been the lack of support from the health care system. However this is something that the couple has learned to expect as it was certainly true during Darren’s life. Yet they have benefited from the continued supportive friendships with people who Darren drew into their lives. This is clearly a time of recovery and also getting reacquainted to each other.

In addition to their shared connection with Darren and having lived through this life-altering experience together, Rana and Sumeet credit their Hindu faith with keeping them together as a couple. It is easy for them to say that they’ve grown as a couple. Their journey with Darren expanded who they are as individuals and as partners: it taught them more about each other and about themselves. Fortunately they have each other, someone who truly understands what they have been through. The videotapes and photographs they have of the family, created while Darren was alive, also serve to validate what they have survived and contribute to meaning-making. The couple’s ability to find the joy and hope in the pain of what they’ve been through has also been part of their bereavement process and a testament to Darren’s teachings. As they live in this different world with each other, Sumeet and Rana continue moving forward with Darren as the captain of their ship and carrying the gifts of his many lessons.

Themes

Narrative of the Interview Process

I would say that the evaluation piece became part of the dialogue after the couples divulged the main body of the story with the embedded details; these could also be characterized as reflections or assigning new or already established meanings to the narratives just told. As individuals, considering their intrapersonal and interpersonal story, the participants remarked on how they have changed and how this event (having a child with an illness and having that child die) has modified how they live and how they view life, their perception of relationships with family and friends, and the important reasons to let their story be heard and acknowledged by myself and others.

Themes that Emerged

The purpose of the project was to document, describe, and understand the lived experiences of couples who have stayed together throughout their child's illness and death, and are now on the journey of bereavement. The objective of the research was to answer this question: What are the narratives of intact bereaved couples whose children have died after receiving palliative care for a life-limiting illness? This question was front and center when I analyzed the content of the 5 couples' stories. The five themes that arose when reading and rereading the texts from the interviews were: (1) the last thing you worry about are issues about us, (2) accommodating one another's coping, (3) recognizing sources of support and limitations, (4) two souls against the world, and (5) we have a common bond: lessons and legacy of the child. Following, I elaborate on each theme and provide excerpts from the couple interviews.

The Last Thing You Worry About Are Issues About Us

In each of the 5 couples' stories, the theme of putting the relationship on hold during their child's life arose. Several of the couples expressed that they were on the journey as a family and after their child's death, they re-encountered their partner in the couple sphere again after what felt like a long time. Gail, wife to Andrew and mother of Elizabeth, captured this sentiment well saying, that after their child's diagnosis "we were ships passing in the night I think from that point on." Don, husband to Christine and father of Michael, expressed that all of the attention was directed at their son and "it just wasn't about us and our expectations." Christine furthered the discussion of the intimate relationship falling down the priority list saying "It's hard enough with a newborn to find time for yourselves. Just all of a sudden it's a hundred times worse than usual and you grow apart a little bit and all you're talking about all the time is [your ill child]." Andrew, in discussing his relationship with Gail, articulated anecdotal evidence of a similar experience to Don and Christine: "I remember we went out for dinner once without the kids. And we actually didn't talk about the kids for a matter of ten minutes. We did well. We survived ten minutes without talking about the kids and what was happening." Annie and Ralph only had quality couple time and dates "once in a blue moon" typically after the encouragement of friends who were willing to baby-sit; lack of money and the rarity of being in the same place at the same time were barriers.

In the case of Sumeet and Rana, they did not "have time to think about us....because all of your energy and effort is spent on trying to figure out what is happening to your dying child the last thing you worry about is the other issues about the us." Creating an image that is possibly representative of the life of parent caregivers for a child with many special needs,

Sumeet remarked that the commitment “is big. Very big. It’s a treadmill existence every day.” In reviewing all of the narratives, it became clear that in situations where parents are concerned about their dying child, it is quite understandable that they are not focused on the me or the we. This appeared to be an approach to coping for the couples as it was a way of focusing on the most pressing issues and not be distracted by subordinate concerns.

Accommodating One Another’s Coping

With this theme, coping encompasses the processes the partners engaged in during their child’s illness and how they currently are managing the emotions in bereavement. Although all of the couples had different circumstances and coped in diverse ways, all of the narratives had this commonality: the individuals in each dyad coped differently than their partner yet they were all able to accommodate one another’s coping needs. They were also able to give each other permission to be in different stages and places as well in dealing with anticipatory and current grief. The men in the study tended to be problem-solvers/action-oriented and the women were typically more emotionally expressive. Despite this difference, all of the partners all seemed to have an implicit agreement not to discuss their child’s possible or pending death. Gail, Andrew’s wife and mother to Elizabeth, found that accepting her and Andrew’s different coping styles was helpful:

I took this course and what it did is it helped me realize that we coped in very different ways. He would go off to work, he could leave, I would write and I would work in my garden. Gardening became very important to me because I couldn’t leave the house. Even when we had caregivers they had to stay so I would get out in the yard and he would sleep. Sleep was a big thing for him. And it used to just and it still

infuriates me. At least at that point, I was able to step back and say ok that's how he copes, that's how he's grieving.

Lindsay, Jack's wife and Jamie's mother, similarly recognized that taking care of her emotional needs, often involving long conversations with her supportive mother, and not expecting her husband to change his communication style was helpful for her and the relationship. Annie and Ralph differed in that Ralph was the more "laidback one" and Annie coped "pretty much with yelling. I'm a perfectionist and bullheaded and so anybody that crossed me would get yelled out...I would just explode on people. And I still do." Ralph commented that they did indeed cope in "completely different ways" and not only accepted his wife's coping style but was amazed by it:

Ummm I don't know how she coped. To this day I don't know how she did it. I really really don't. I mean I'm amazed at how she dealt with this. Because most couples the husband's home at 5 o'clock. Me I was gone. So this was left to her and I don't, I still to this day don't know how she did this on her own....She never asked for help she never told me I had to quit my job and do something different. She accepted it the way it was. Well it amazes me. It totally amazes me. To this day if anyone says to me how did you do it. I say well I didn't do it, my wife did it. I'm blown away by it....We would go to bed and she would cry, "I'm just so tired I'm worn out." I was doing as much as I could when I was home but there were 6 days a week that she was on her own. Not once did she let the kids see her cry. Let the kids see she was tired.

Despite managing their feelings differently, it was clear in the narratives of some of the couples that the partners in the relationship were in tune emotionally, possibly allowing for greater acceptance and empathy. Don and Christine recalled a family road trip after their

son died. They told a story of driving along and hearing a song on the radio and it was a “happy family moment” but soon after, Christine began crying because the absence of Michael was so pronounced. Christine said about Don:

At least we understand how it’s like. Like he never gets after me for wrecking a happy moment and I don’t ever do that either, like we’re just both there.

Recognizing Sources of Support and Limitations

The topic of support for each of the couples was emotionally laden. Before and after the death of their children, it emerged in the couples’ narratives that external support was not consistent. Insufficient or removal of support as well as resources that strengthened them as individuals and as partners surfaced as vital themes across the couples’ narratives. Support in this context can be conceptualized as both something the individual parents and couple received externally or from within themselves or their relationship.

Canuck Place, the Vancouver children’s hospice, was identified by all of the couples as providing enormous support. It was also obvious that Canuck Place was for all of the couples, and for some, continues to be, a special place of connecting to other parents who truly understand the emotions and experiences of have a dying child or to be bereaved. All of the couples spoke of the importance of having their experience validated and normalized by other parents undergoing similar journeys. Jack, Jamie’s father and Lindsay’s partner, said that through building relationships with others in the grief support group ran out of Canuck Place he and Lindsay “have learned....you’re not the only one who has gone through this.” Receiving support also seemed to increase their empathy for others and gave them a greater understanding of what grieving parents might need. Jack said: “I think what you realize is that people don’t mind you recognizing that they’re maybe going through a tough

time.” For Lindsay and Jack, the support group at Canuck Place also helped them be hopeful while Jamie was still alive. Sumeet, father of Darren and husband to Rana, found that it was at Canuck Place that he and his wife realized that they didn’t have the “biggest cross to bear;” which was humbling and heightened their interest in not only advocating for their family but others who were in a similar situation.

Sumeet described Canuck Place metaphorically capturing the sense of isolation and needed connection experienced by many of the couples saying that without Canuck Place “being born it would be hard for people to survive alone on the island. If anything, Canuck Place brought all the people off the island and put them in a central place.”

Three of the couples took advantage of the respite from care-giving that Canuck Place offered; clearly the hospice understood for them the need to take breaks from this physically and emotionally exhausting duty. Christine and Don went on an anniversary trip while Michael was cared for there. Gail and Andrew recall these breaks as helping them “get a sense of what life would be without [their daughter]” —helping them to begin the transition into bereavement. Gail spoke about the blend of excitement and guilt that accompanied trips away from Canuck Place while their daughter Elizabeth remained at the hospice:

Well on one hand it was heart-wrenching but on the other hand, I was giddy. It was horrible and I think to this day I still have guilt. Because it was like oh oh I can have a life. We sat and we did sit and talk about that like I feel so excited I have a life and can actually go and do things but also oh I feel so guilty. So we had a lot of conversations about that and I talked to the therapist about that. And we had a nurse at that time who could do respite and she said you guys should go away for a week. And that was a big step. Very big and then we had a few weekends after that.

For two of the couples, spiritual beliefs and being involved with religion, was linked to keeping the couple relationship intact. Gail and Andrew, Jehovah's Witnesses, found comfort and support in the 3 meetings a week with their "spiritual family." Rana and Sumeet attribute their Hindu faith as being an important factor in keeping them together.

In comparison to their relationships with care-giving and/or bereaved parents, many of the couples commented that their relationships with friends, and sometimes family, were lacking in support. It was mentioned by two of the couples that friendships ended during this traumatic period in their lives. Jack said that "I think outside relationships factor into how much you need each other" and went on to discuss that a lack of external support can put a strain on the couple relationship. In their story-telling, Lindsay said, with regards to friends:

[They] are not there for you when you need them. Yeah the people that you thought you could lean on weren't dependable and the people you weren't expecting support from, I'm sure you've heard this a lot, really came and showed their support. Yeah it was definitely an eye-opener. To see who wanted to journey with us

Three couples spoke of the need to thrust themselves into advocacy roles and proactively seek external support to properly care for their child. In each of their stories, it appeared that they transitioned from being advocates solely for their family to extending themselves in an attempt to help out all families suffering in similar circumstances. Andrew found that "we [he and Gail] learned about how to assert our needs and it wasn't to demand it but to expect it." Sumeet and Rana also expressed that as a couple they found the resources within themselves to gather the help they needed. Sumeet said: "I used to be a very quiet person and after... going through his journey I became quite an advocate and I had to speak

up more and more and talk about issues as they were and that was a totally different side to me.”

Ralph and Annie, parents of Justin who had Duchenne’s muscular dystrophy, found themselves drawing on their “bullheadedness” with health professionals and the school system on a regular basis; often feeling like they knew more about how to appropriately care for their son than even the doctors. They shared the same “attitude” in approaching their son’s treatment and care and were able to be proactive because they had the other’s support. Having their partner’s support proved to enable the caregiving parents to muster up the courage and energy to cope with the trials and tribulations associated with their child’s illness and treatment.

Two Souls Against the World

“Because most people can’t believe that we’re still together and that we’re not at each other’s throats blaming each other,” Ralph, Justin’s father and Annie’s wife, remarked. Ralph’s comment illustrates a popular misperception that relationships are not resilient enough to handle extreme stress. Through holistic and content analysis, it appeared that all of the couples share this powerful experience: That the couple relationship was/is a refuge, a place of being understood, and a source to draw strength from. This theme emerged because in all of the couples’ narratives, there was a message that all of these parents have fought hard to survive and they have done it as a team. Christine, Don’s partner and mother of Michael, expressed that their marital relationship was a zone of peacefulness in the midst of chaos related to their son’s illness and treatment and they “were like two souls against the rest of the world.” Likewise, Ralph expressed that he drew a lot of strength from Annie and “if you listen to her she’d say she drew it from me...I would draw my strength from her and

that's what would keep me going and it still does." Ralph narrated that he would watch Annie care-giving and "you'd have to be completely numb not to be inspired by someone like that."

Rana and Sumeet view themselves as having been living on an "island" away from the real world; they have been on a spiritually profound journey as a *couple*. After their son Darren's diagnosis, they really perceived a change in the way they were approaching life and being in the world compared to their couple friends:

It changed our perspective on a lot of issues. We were living in isolation and our ideas on certain things were very very different. We found our ideas on a lot of stuff very very different. We found other couples were interested in fashion, going to the movies... and a lot of the other families other normal families would be concerned with material wealth and everything else associated with it.

Several other couples expressed a similar sense of being in a different world than many of their friends and that their partner is their best friend.

A comment of Lindsay's, Jack's partner and mother of Jamie, illuminates clearly how elemental intimacy and love are in surviving tragedy:

We were already very close. So I don't think it's driven us apart at all. I mean we were saying before there are different frustrations and stresses thrown in there but we are dealing with them we are able to deal with them and know how to deal with them in a healthy way. You know directed towards each other. I think we both respect each other and yeah and not let it interfere with our relationship.

Jack added to the discussion saying, "We're still in love and we still have issues about how we are as individuals and what we want from each other but I don't think it changed." Three

of the couples perceived their relationship as having grown through the experience of caregiving for their child and being in bereavement. When describing posttraumatic growth, two of the couples spoke specifically about learning more about their partner. Andrew said: “I know what she wants to do before she even does it. There are many things. In many ways we have definitely grown as a couple.” Gail added, “We still argue. That sorta thing. We’re normal people. We definitely have way more patience than we ever used to.” The couples who would not use the term ‘growth,’ felt that their relationship was already strong but hadn’t been changed by the process. Whether the couples in this study described their relationship as having grown or not, the couples’ stories were about spousal connections that remained intact during and after the incredible trauma.

We Have a Common Bond: Lessons and Legacy of the Child

The thread running through all of narratives were the lessons learned about life and death from the deceased children. The narratives disclosed contained the voices of all of the couples’ deceased children and appeared to keep these children’s messages and spirits alive. What emerged in analyzing the stories was the strong—and, possibly, immortal—attachment the partners have to each other because of their common bond to the child. It was clear through hearing and analyzing the narratives, that identifying the lessons and legacies of the deceased child were the couples’ and families’ way of making-meaning. Ralph, Annie’s husband and Justin’s father, said, “Justin will always be part of both of us and that’s the way we look at it. I could never see us going in different directions because we have a common bond.” For Gail and Andrew, parents to Elizabeth, making-meaning of this experience not just with each other, but with their other daughter has been an important activity because they all lived through it. Christine, Don’s wife and Michael’s mom, commented that “a huge

dynamic” between her and Don is their living son. In essence, these are families who have survived tragedies as teams and will forever be bonded for that reason.

With reference to lessons learned, Lindsay, Jack’s partner and Jamie’s mother, spoke of how easy it was to be positive and find purpose in life while Jamie was still alive and now their goal is to find new meaning in life as a way of honoring him:

Jamie embraced life. He never had a down moment....So I think that’s an important lesson to take forward. You can emphasize the negative about what’s going on or the positive.

The aliveness and love for life was mentioned by Ralph as well when speaking of his son: “This kid was full of life. From the second he got up in the morning till the second he went to bed at night this kid was full throttle, wide open, and go. There was no slowing him down.” Justin’s sense of humor, in addition to being energetic, taught Annie and Ralph to not take anything for granted, to not feel sorry for themselves (because their son did not), and to be fighters.

Darren, Rana and Sumeet’s son, “has been a great teacher.” Sumeet expressed that Darren taught him about his strengths and that Rana and he “entered the university of life by doing this journey with Darren.” He continued, “Because we picked up new life skills that we would not have picked up had we had a normal child. And that in itself was a gift.” One of the skills that the couple learned was the importance of maintaining peace in their home as Darren picked up tension easily. Consistent with what all of the other parents said in the study about their children, Sumeet commented that his child’s “spirit is very strong” and:

Every so often we see strange people dropping out of the sky and knocking on our door and popping in and we often wonder why the person is here but we also know the answer. Darren sent them.

Leaving lessons and love behind, the deceased children of the parents interviewed for this study will never be forgotten. These children's lives and deaths have left permanent impressions on their families and have clearly influenced the bereaved couples' ways of interacting with each other, others, and the world.

CHAPTER 5

Discussion

If I could

I'd protect you from the sadness in your eyes

Give you courage in a world of compromise

Yes, I would

If I could

I would teach you all the things I've never learned

And I'd help you cross the bridges that I've burned

Yes, I would

If I could

I would try to shield your innocence from time

But the part of life I gave you isn't mine

I've watched you grow, so I could let you go

If I could

I would help you make it through the hungry years

But I know that I could never cry your tears

But I would If I could

Yes, If I live

In a time and place where you don't want to be

You don't have to walk along this road with me

My yesterday won't have to be your way

If I knew

I would try to change the world I brought you to

And there isn't very much that I could do

But I would If I could

From Ray Charles' song "If I Could"

Ray Charles so beautifully touches on a parent's painful recognition that they cannot protect their innocent child from the struggles of life. This study explored the narratives of couples who could not protect their child from death. Illness tragically took these sons and daughters away. Through the process of interviewing, transcribing, and, finally writing, these co-created stories were analyzed with the intent of learning about what spouses go through together as they transition from their child's diagnosis into palliative care and as they negotiate the terrain of bereavement. The stories share common threads. Weaving these stories together were the themes: the last thing you worry about are issues about us, accommodating one another's coping, recognizing sources of support and limitations, two souls against the world, and we have a common bond: lessons and legacy of child. How do the findings of this study relate to the current literature on grief, coping with loss in relationships, and parental bereavement?

The Last Thing You Worry About Are Issues About Us

For parents of children diagnosed with life-limiting conditions, grief starts early and losses start multiplying fast. As Doka (2007) emphasizes, the current understanding of grief is that it is a "widespread reaction to loss" (p.89) and we should rid narrow views of it as

simply an emotion following the death of a loved one. Rando (as cited in Doka) furthered the understanding of grief by introducing the concept of anticipatory grief and its partner—anticipatory mourning. Rando defined anticipatory mourning as a response “to all the losses encountered—past, present, and future—in the course of an illness” (Doka, p. 89). Losses can occur in the area of relationships and several of the couples referred to losses or disruptions to their couple relationship during their child’s illness and into bereavement. When asked about their intimate relationship, some of the couples’ answers supported Hagemester and Rosenblatt’s (1997) finding that sexual intimacy for bereaved parents can be difficult, whereas for at least one couple, this part of their relationship did not seem to be impacted. Conversely, another couple stated that their intimate life had been dramatically affected by their child’s illness and death.

Cook (1984) in her investigation of problems parents encounter while care-giving for children with cancer found that couples’ sex lives typically suffered during the child’s illness for logistical reasons and because one or both partners were emotionally and physically exhausted. Dissimilar to Cook’s finding that mothers “maternal obligations came first and spousal duties” (p.80) came second, with the fathers feeling frustrated and left out by this, all partners in my study appeared to be in agreement that this was not the time for the relationship to be a priority. This finding was compatible with what a participant in Jones and Neil-Urban’s (2003) study of fathers of children with cancer said about his spousal relationship, “Romance?—it’s not a priority. We’re partners right now...not a couple” (p. 55).

The loss of time and energy for the relationship, during the child’s illness, was clearly part of the experience for all five couples. Davies et al. (2004) observed that husband/wife

relationships were put under “considerable strain” (p.125) during a child’s treatment for a life-limiting illness and that couples typically only had the time and energy to discuss practical concerns. This was echoed by all couples I interviewed; they all discussed how they were essentially forced into being in the here and now because there were so many practical, urgent issues associated with caring for their child, that they did not have time or energy to focus on their feelings or their relationship with each other. There also seemed to be a psychological reason for not entering into emotionally-charged conversations. *Rules*, in family system’s terminology, can be explicit or implicit and they “characterize, regulate, and help to stabilize how-and how well-families function as a unit” (Goldberg & Goldberg, p. 74). Across couples in my research there appeared to be an implicit rule not to discuss their child’s pending or possible death.

Steele’s (2002) finding that couples care-giving for a child with a terminal illness were “so busy concentrating on the ill child” (p.426) that they neglected each other and their marriage, but that it was their marriage that glued the family together and allowed them to survive such a difficult undertaking, is the greatest parallel to what I found about the 5 couples’ relationships during their child’s illness.

Accommodating One Another’s Coping

Partners were introduced into the world of grief together after becoming aware that their child would die from his or her illness. Steele’s (2002) study of families care-giving for a child with a terminal illness highlighted the large influence communication has on a couple’s ability to successfully endure such a stressful experience. Steele found discrepant views and coping styles created conflict for parents but that when they accepted their differences, the divergent perspectives could be a source of strength for the marriage. This

finding is consistent with the result from my project that suggested that when partners were able to accept and accommodate their spouses' way of dealing with stress and grief, the couple realm was relatively easy to exist in. Steele's and my finding are also congruent with relationship-focused coping theory (O'Brien & DeLongis, 1996). Relationship-focused coping refers to methods that aim to preserve and assist relationships during stressful periods. From this theory's perspective, partners do not necessarily need to cope in the same ways but have styles that complement each other. Badr (2004) adds to the discourse on relationship-focused coping by explaining that the key is for both people to be actively engaged in decision-making and problem-solving.

Kamm and Vandenberg (2001) explored whether speaking about grief helped couples cope with it and feel more satisfied in their relationship. They discovered that positive attitudes about communication resulted in lower levels of grief in the long run. Along the same vein, Traylor, Hayslip, Kaminski, and York (2003) found that in grieving families, dyads who did not value open communication about the loss experienced greater grief consistently for a longer period of time. Communicating openly might not even be sufficient. Riches and Dawson (1996b), in hearing the co-created narratives of bereaved couples, learned that the degree to which their married partner provided a sympathetic and uncritical audience to their grief impacted whether or not the participants described their marriages as strong. These research results relate to the findings that emerged from my study in that it was obvious that having open lines of communication and a 'safe landing spot' in the relationship, helped the couples integrate their emotions into their daily life before and after their child's death. Although there may have not been the time, energy, or emotional capacity

to talk about their emotions during their child's illness, knowing that they could go to their partner to discuss anything appeared to be helpful with all of the couples.

O'Brien and DeLongis (1996) also point out that beneficial strategies are using empathy, accommodating the other person's communication style, and being able to compromise. It was clear in all of the interviews that each individual was actively participating in the experience of care-giving and now coping with bereavement; each partner was certainly "pulling their own weight." With respect to compromising, two of the couples made direct reference to learning how to compromise and the positive consequences for their relationship that came from that.

Compatible with Jones and Neil-Urban's (2003) finding that fathers tend to use active coping strategies, like becoming advocates or information-gatherers, the fathers in the present study all referred to veering towards those coping methods as well. Although, it must be stated that moving into advocacy roles was spoken about by both the women and men in my study. Littlewood, Cramer, Duncan, Hoekstra, and Humphrey (1991) in their research with bereaved parents found that mothers tend to use "palliative, passive, comforting thoughts and emotionally expressive styles of coping" (p.3) and the five mothers participating in my project validated that finding. Accepting different styles within the partnership proved to help all of the couples to smoothly navigate the road of illness and bereavement as a team.

Recognizing Sources of Support and Limitations

Narration on the topic of support was often full of emotions—helplessness, hopelessness, frustration, anger, hurt, as well as a sense of building strength and newfound empowerment. In the literature on parent caregivers of children with life-limiting illnesses,

experiences of support, and, more frequently, lack of, contain equally emotionally complex stories. Steele (2002) learned in her study of families coping with caring for a terminally ill child that parents often do not feel supported by or that they can trust or rely on the care of health professionals. This notion repeatedly came up in the interviews in my study. Two couples emphatically talked about knowing more about their child's healthcare needs than the doctors and one father stated that there is no manual for parents when they begin the scary journey of caring for a child with a life-limiting condition. Couples, similar to what was found in Steele's and Jones and Neil-Urban's (2003) research, had to become more resourceful because the help was not always readily accessible, visible, or there at all.

Klass (2001) passionately reiterates the importance for bereaved parents to keep their deceased child's spirit alive and that it can be achieved by interacting with people in their community who recognize the death, are mourning it, and where a continuing bond with the child is validated and shared. Lang, Gottlieb, and Amsel (1996) found that bereaved couples benefit from maintaining social networks in which they are both involved. Four of the couples expressed the importance of shared social groups, particularly groups informally or formally set up to cope with grief. The Canuck Place Parent Grief Support Group was talked about by three of the couples as being almost a life-preserver before and after their child's death. All of the couples talked about relationships with friends and family: With some relationships continuing to be supportive, safe spaces to deal with grief and other relationships ending or not being satisfactory. Similar to Cadell's (2005) finding that friends do not always continue support after the death of a child, two couples in my study talked about friendships disintegrating during and/or after their child's illness.

All of the couples spoke of the difficulty of trying to go back to “normal life” after becoming accustomed to the routines associated with caring for their child, and, of course, having their child alive. These routines included health care workers, such as beloved nurses, chaplains, helpful doctors, occupational therapists, psychologists, and social workers. This relates to Contro, Larson, Scofield, Sourkes, and Cohen’s (2004) description of the withdrawal of support from health professionals as being a profound secondary loss. This should not be minimized.

Unlike Farnworth and Allen’s (1996) finding that bereaved mothers do not get the understanding and support they need from their partners, the partners in this study, as aforementioned, were empathetic and responsive to each other’s needs and knew that the other understood what they were going through. Hence, a lack of support within the couple relationship was not an issue in this study.

Two Souls Against the World

The father participants in Jones and Neil-Urban’s (2003) study used the metaphor of “brave fighters” in describing their children with cancer. I would use, in addition to “two souls against the world” which was created by a father in my study, the metaphor of “brave fighters” when describing the couples who shared their stories with me. In their stories, I heard survivors’ discourse and saw each couple as being compatriots who have been through a battle together; have returned from war. I have wondered: Does the stability of the relationships of the couples participating in the study create a safe space to focus on the parents’ grief, and accompanying emotions, as well as deal with practical tasks? (e.g., returning to work, raising other children).

In congruence with the Dual Process Model (DPM) of coping with bereavement (Stroebe & Schut, 1999), grief was talked about by the couples as being a dynamic process and embedded into their lives from the beginning of their child's diagnosis and now in bereavement. The DPM views coping as involving 2 parts: 1) loss-oriented coping and 2) restoration-oriented coping. Participants who have living children particularly seem to oscillate between loss-oriented coping and restoration-oriented coping. Perhaps the living children serve as anchors and important reminders to the couples to be engaged in life and the matters at hand. Nonetheless, blatant in all of the couples' stories was a sense that their loss is at the core of their lived experience and although they may take time off grieving, as the DPM would describe, their grief is always there. But at least they are joined by their best friend in coping with it—their life partner.

Family systems theorists view families as exceptional at maintaining *homeostasis* yet, as Nadeau (1998) and Gilbert and Smart (1992) found in their respective studies of families dealing with loss, death can powerfully disturb a balanced system. Similar to Gilbert and Smart's discovery about couples whose children died in infancy or as fetuses, the couples in my research went through a trajectory of instability during their child's illness to an increased sense of stability at some point after their child's death. Several of the couples mentioned a "re-encountering" of each other in the romantic realm following their child's death but that their closeness to each other was consistent throughout the experience. Yet another similarity to Gilbert and Smart's findings was that social support within the couple relationship contributed to making-meaning and healing for the participants.

Couples spoke of desires to reignite their passion for each other and find a "new" normal. This focus also relates to the DPM of coping with bereavement. Perhaps a child's

illness and death can destabilize a spousal relationship temporarily but the relationship will find homeostasis again when life becomes more settled.

My findings regarding the bereaved couples' relationships as being strong and as having formed an unbreakable bond converge with Najman, Vance, Boyle, and Embleton (1993) findings that bereaved couples and non-bereaved couples do not differ in terms of quality of their marital relationship. Yet conversely, the results from my research did not agree with Schwab's (1992) finding that the death of a child puts a couple's relationship in danger because of major relationship problems such as, withdrawing from one another, fathers' worry and frustration over their wife's grief, wives' anger over husbands not being emotional enough, communication difficulties, and decrease or loss in sexual intimacy. Of course, though, the sampling strategy for my research likely excluded couples who were having major difficulties.

Parents whose children are diagnosed with, and then succumb to, life-limiting illnesses go through many life-altering role and status changes. The parents in this project discussed the dramatic change of being catapulted on to the care-giving parent path after believing that they were going to be parents to healthy children, and then, of course, being pushed into the world of the bereaved and existing in what Dawson and Riches (2004) calls living on the other side of the border—what I call, “the bereaved territory.” Fortunately, as the parents in this research relocated to this territory they had their partner to turn to and be at home with.

We Have a Common Bond: Lessons and Legacy of the Child

Closeness and open communication about feelings and thoughts appear to create a fertile ground for meaning-making about the child's life and legacy to occur. Gilbert (1997) asserts that families can serve the function of being a "meaning-making environment: A place where members are able to test their understanding of their own or their family member's dying, the dying process itself, and what all of this means for their own experience of life and death" (p.272). Gilbert's notion was validated by the couples. Stated both explicitly as well as less overtly, all couples in the research project shared that their relationship and the family environment was one where it was safe to grieve and reflect on their deceased child's life and legacy. Nadeau (1998) found that families construct meaning together after a loved one dies and the couples in this study are certainly doing this.

Walter (1996) proposes that the purpose of grief is for the bereaved to integrate the memory of the dead into their continuing lives. Grounded in post-modernism, Walter contends that people have a strong need to make meaning of their continually changing life narrative that both involves and does not involve the deceased. Through their conversations, story-sharing with each other, other family members, and friends, reviewing photos and videotapes of their family during their child's life, engaging in meaningful activities together, and concentrating specifically on what they learned from their child about living and dying, the couples in my research are making meaning of their stories that will always involve their deceased sons and daughters.

Like Nolen-Hoeksema and Larson (1999), Cadell (2005), Tedeschi and Calhoun's (2004) discoveries about personal growth after traumatic events, the bereaved parents and couples in this research project experienced transformation through this lived experience. In

line with Tedeschi and Calhoun's model of posttraumatic growth, they all expressed co-existence of growth (e.g., lessons learned, changed view of life and relationships, realization of inner strengths) and immense distress and enduring pain. For some of the couples, spiritual ties, or experiences, with their deceased child have helped them to continue evolving personally and as a family. And for all of the participants, it was clear that their child's life, and their experiences caring for that child, will never be forgotten. Their love for each other, and interminable bond as a family, is a testament to that.

Partners in Grief: Implications for Health Care Providers

There is no guidebook given to parents to help them negotiate the rocky terrain of caring for a child with a life-limiting condition. It is an unpredictable, and scary, road to travel on. Understandably, these caregiving parents turn to their health care providers for direction, to act as a compass for them. All of the couples in the study referred to the foginess of this illness path and how health care providers sometimes made it clearer and more manageable and at other occasions, did not.

Three of the couples spoke of the need to be strong advocates for their ill child and their family in order to get their many needs met, to make their paths smoother. Compatible with participants in Contro et al.'s (2004) study, these parents spoke of perceived deficiencies in the health care system, poor communication and conflict with health care providers, being forced into advocacy roles, and lack of support in bereavement. One might wonder if some families who cannot assume the role of advocates might fall through the cracks and not get the support they need.

The stories and themes that emerged in this research should grip the minds and hearts of health care providers working with families who have a child with a life-limiting illness

and urge them to evaluate their own and others' practices. As Contro et al. (2004) underline, these families have multiple and diverse needs and concerns and the more emotional and practical help they can receive hopefully the easier it will be for them to walk this traumatic path.

In the least, I would encourage all health care professionals working with families in this situation to use empathy; to try their best to understand and empathize with the emotional and cognitive experiences of parents of children diagnosed with a life-limiting illness. This might help in creating relationships that the parents can turn to for comfort, a sense of safety, and a way of decreasing isolation during the difficult times. If families can feel that each person on the health care team is warm and understanding perhaps this will counter-act the frigid weather of their journey. I am aware that medical schools are bringing empathy training into their curriculum. Perhaps all health care professionals working in the area of pediatric palliative care could be required to take empathy training.

Indeed, one of the issues brought up by three of the couples in the study, was how doctors delivered difficult news. The following excerpt from an interview with Gail in the study illustrates this point:

The way we found out was that I happened to be at the hospital for dental, Elizabeth had some dental work, I had the two kids and I was getting ready to leave in the car and the doctor came up to me and said oh oh oh by the way we just found out, we just got the results back and she has a progressive neurological disease and someone will call you. So I don't to this day how I got home. I have no recollection how I got home. So I told Andrew and we both sat around in shock until (m-until the call came) I don't know how long...

From diagnosis into bereavement, parents whose children live with and die from a life-limiting illness deserve to be treated with respect and appreciation. These families endure a struggle that most believe they could never have the physical and emotional strength to manage. As helpers, health professionals are put in the position to use their energy, knowledge, and skills to aid these unfortunate families. While watching the suffering and the rockiness of the road these families are travelling on, health care professionals are given the opportunity to pull from deep inside their hearts and minds to contribute.

Partners in Grief: Implications for Counselling Psychology Practice

Here I present the summary of what I learned from this research project as it pertains specifically to the field of counselling psychology.

Grief isolates. As counsellors, our duty is to help reduce clients' experiences of isolation. The counsellor, because they are a person too, possibly even a parent, might feel emotionally and mentally challenged—perhaps, helpless—by working with parents who have lost a child. Questions that could arise in the counsellor's mind might be: How can I wrap my head around something that is devastating, unexpected, and enormously unfair? How can I help bereaved parents accept something that is so unacceptable? How can I assist the bereaved in creating positive meaning out of an event that perceptibly is without benefits?

First and foremost, I believe offering empathy and validation should be a main focus for the counsellor. This is not dissimilar to what is helpful in the relationship of the bereaved couple. Counselling, for bereaved individuals and families, should be a place where it is safe for grief to be brought in. Where the counsellor attempts to understand the unique grief pathway that the individual or family is on and where suffering is accepted, empathized with, and explored. I heard from couples in my study about how uncomfortable, draining, and

unsatisfying it is to leave their grief out of the picture when they are around people who would not “go there” with them. This research project emphasized to me that grief is a narrative and complex process and that through verbalizing, and having acknowledged, one’s experiences of suffering and strength-building, healing may begin.

The grief pathway is different for every individual. Each family will also manage grief uniquely as they are influenced by their own values, beliefs, histories, culture, spirituality, and context. As counsellors intent on helping bereaved parents cope with the trauma of losing a child, it is important to look to the parents to guide the way and inform you about how they want to travel in bereavement and to realize that there is no one way or right way to grieve. Some might be more loss-oriented and others more restoration-oriented. It is all normal. Indeed, normalizing bereaved parents’ distinctive grief processes should be essential to any grief counsellor’s work.

Spirituality and sexuality should not be ignored. In this study, I learnt the importance of inquiring about these facets of the couples’ bereavement process. It has been confirmed by empirical research that therapists often avoid asking about clients’ spirituality (Brotherson & Soderquist, 2002). Two couples in this study explicitly discussed how their faith has been a significant ally in their grief processes; indeed, their spiritual frameworks were a huge component of their narratives. Brotherson and Soderquist strongly encourage therapists to learn about whether a child’s death has affected spiritual or religious beliefs or if spiritual beliefs or practices serve as an important role in helping parents cope with their grief.

Spirituality or religion may or may not be used as a source of support and I would suggest that counsellors do some questioning around the spiritual aspect of the individual’s or family’s life. Some individuals may find comfort and meaning in continuing a

relationship with their deceased child; whereas for others, it is helpful to find closure in that relationship and begin moving on. One family in this study explained that their spiritual beliefs are that their child is dead and that they will reunite with her one day in heaven but not until then. Other families talked about continuing relationships with their deceased son or daughter.

Some couples in the study mentioned that having an ill child or being bereaved impacted their sexual and intimate relationship. This confirms empirical research that has produced similar findings (Hagemester & Rosenblatt, 1997). I think that counsellors working with bereaved couples should address the sexual relationship of the couple and be prepared to normalize for clients experiences of difficulty with intimacy. Exploring with couples what intimacy means to them might be a good start. Secondly, I would suggest investigating collaboratively what helps and what hinders their intimate relationship. Focusing on what would assist in reigniting their romantic bond might be a useful intervention in helping them slowly return to normalcy and enhance their connection to each other. For example, during a child's illness, even during the palliative stage, counsellors might suggest that the couple make some time for just the two of them if they can. Questions counsellors might ask to catalyze the process are: "What made you fall in love or love your partner in the beginning of the relationship?" "What were some things your partner did that made you feel accepted, appreciated, and excited?"

Counsellors should keep in mind the value to relationships of having couples utilize helpful relationship-focused coping strategies, such as: compromising, accommodating one another's coping style, and empathizing. A couple in the study stressed to me the enduring

benefit to their relationship that came from understanding and accepting the other person's different way of dealing with their feelings and their grief.

Using interventions that will help the partners increase their empathy and empathic behaviors toward each other—facilitating healthy relationship-focused coping—could be very fruitful. A counsellor might pose these questions, “What are some ideas you have about what would best help your partner cope with their grief?” For example, a wife might mention that her husband would probably appreciate getting to go out with his friends more. The husband, in this scenario, might reciprocate saying, “I think my wife would prefer if I made more time for us to talk about our son who died.” Together, with the counsellor, the couple might agree to a contract to support their partner by enacting specific helpful behaviors.

Finally, as a researcher, training counsellor, and bereaved individual, I fervently believe that meaning-making is essential prior to and in the aftermath of a loved one's death. It is also not always an easy thing to accomplish. Recent literature has called for the use of narrative exercises and life review (e.g., Gilbert, 2002) in working with bereaved individuals because of the potential for meaning-making. The couples who contributed to this research all expressed that benefits were gained through telling their stories. One couple e-mailed me and said that having their written story gave them “something tangible to hold on to.” Another couple during the interview remarked that although they had “told their story many times” they were surprised by the novel revelations that arose in the version they shared with me. Throughout all of the interviews, I observed participants being surprised by information flowing from their partner's mouth. New discoveries about one's self and one's partner can come from story-creation.

Through individual and collaborative biography-making, couples' relationships might benefit not only because the partners are getting a chance to learn more about each other but have their relationship solidified by storying a shared journey. They are making-meaning together. Through telling their stories, the bereaved parents were able to have their experiences heard and validated not just by me but by their partner. They are bearing witness to each other's powerful processes. Co-creating stories in counselling for the aforementioned reasons should be a part of work with bereaved couples.

For those bereaved couples with other children, redeveloping or maintaining their relationship, unarguably, has positive implications for the family system. I hypothesize that when parents have a stable, loving relationship their children have a greater sense of well-being and adjust better to life's transitions. A stable partnership creates the foundation for a stable home.

Implications for Future Research

Research on couples undergoing bereavement following a child's death can go in as many directions as there are stories about this unusual tragedy—thus, many. Given that this study was limited with regards to diversity and sample size, one place to begin with a new project would be to enhance the number of couples as well as enroll a more varied sample. It would be useful, considering the multiple ethnic and cultural backgrounds, and design of families in Canada, to replicate the study and include non-heterosexual partners—gay, lesbian, bisexual, transgendered—as well as more couples who are not Caucasian. Implementing a longitudinal method could also generate interesting and important findings about the long-term outcomes of child-loss on couples. A longitudinal design exploring the lives of bereaved couples might inform health professionals, and the general public alike,

about what changes take place over time as bereaved couples continue walking the path of bereavement together; about what keeps a relationship working not only 10 years after the loss, for instance, but 20; and about how couples continue to learn from their loss as the years pass.

Three of the couples in this research lost children to hereditary diseases. A study focusing on the experiences of couples whose children die of these particular illnesses could provide information about the unique impact these illnesses, and deaths, have on the spousal relationship. For instance, learning more about the decision-making issues these bereaved couples might encounter about having more children could be useful for health professionals, and the public, to know about.

Another way of becoming more educated about successful bereaved couple relationships could come from expanding our understanding of the grief processes of each gender. This might include conducting separate interviews for the males and females so that we get a more in depth narrative from each partner and their journey. A study comparing intact couples to spousal partnerships that are severed during or after a child's life-limiting illness could also be very instructive. Hence, another research project that could extend what I have done is a study using an intact bereaved couple sample and a sample of divorced or separated bereaved couples and single bereaved parents. Another comparison study that could produce valuable findings would be exploring the differences between bereaved couples who have remaining children and those that lost their only child. How does their identity of parents change when they have lost their only child? Yet another study that could provide rich and useful data, and one that could potentially validate the themes presented here, could use a grounded theory method. Using 15-20 couples, a grounded theory study

could generate a theory and model about how couples *do* cope through such a trauma. For couples who are care-giving for a child with a life-limiting illness or who have lost a child to this type of condition, having a validated model to look to as a way of guiding them through their couple processes could be very helpful. This would also be of great value to helping professionals who work with bereaved parents and couples.

Conclusion

Rallison and Moules (2004) use the term ‘cloaking’ to describe how we veil the reality of children dying perhaps in hopes that if we pretend it is not there, it will disappear from our psyches’. When we remove these cloaks, though, we are able to get closer to an unfortunate reality—that children *do* die. One father in the study used the metaphor of “islands” to describe how care-giving families of children with life-limiting illnesses are living on their own islands: They are isolated from reality and from others. One reason these families might feel removed from others—and this was noted by several of the study participants—is because of the intense nature of being a caregiver which requires living an existence that revolves around care-giving. As one parent called it, a “treadmill existence.” Still, similar to the cloak metaphor, there is an implication that dying children are hidden from society because it is too painful and too anxiety-provoking for the majority of people to handle confronting. Beaker (1973), in his classic book the “Denial of Death” argued we are a death-denying society. We are frightened of facing our own mortality. But what happens to the parents who are forced to face mortality because their own children are dying?

The stories presented here are about the helplessness and hopelessness couples come up against as they face their child’s death. They are about the bevy of activity and the associated stress that continues until the last breath is taken by their son or daughter. Yet

they also all contain multiple messages about hopefulness and psychological and emotional perseverance.

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Appendix A:

Ethics Approval



The University of British Columbia
 Office of Research Services
Behavioural Research Ethics Board
 Suite 102, 6190 Agronomy Road, Vancouver, B.C. V6T 1Z3

ACKNOWLEDGEMENT LETTER

PRINCIPAL INVESTIGATOR: Maria Buchanan	INSTITUTION / DEPARTMENT: UBC/Education/Educational & Counselling Psychology, and Special Education	UBC BREB NUMBER: H06-80535
SPONSORING AGENCIES: Unfunded Research - "Partners in Grief: Couples' Narratives of the Transition from Pediatric Palliative Care into Bereavement"		
PROJECT TITLE: Partners in Grief: Couples' Narratives of the Transition from Pediatric Palliative Care into Bereavement		
This letter will acknowledge receipt of the following document(s) regarding the above-mentioned study:		
DATE OF ACKNOWLEDGEMENT: June 13, 2007	Completion of Research	

*Acknowledged on behalf of the Behavioural Research Ethics Board
 and signed electronically by:*

Ms. Shirley Thompson, Manager

Appendix B:
Letter of Invitation

Dear Mothers and Fathers,

I am a master's student in Counselling Psychology at the University of British Columbia (UBC) and am conducting interviews, as part of my thesis research, with couples whose children have died after receiving pediatric palliative care for a life-limiting illness. I am very interested in hearing the stories of intact couples who have gone through this experience and are now in bereavement. Specifically, I am hoping to learn how married couples cope together during their child's illness, through palliative care and into bereavement process.

I understand that this is a challenging and emotional time for you and the prospect of talking to a stranger about your personal experiences may seem daunting. However, I am hopeful that these interviews might be personally beneficial in the sense that telling one's story can be meaningful and helpful in the grief process. I also plan, as the listener, to provide a warm, safe, and supportive environment to listen to your story. The interviews will be done at a place of your choice and where you are most comfortable. I am able to travel to meet with you if you live anywhere in British Columbia.

If you have been bereaved for a minimum of 1 year, are in a marital relationship that you would describe as "intact" and that began before your deceased child was diagnosed with a life-limiting illness, and **both you and your spousal partner** are interested and willing to share your experience, please contact me. I would be happy to answer any questions you may have. Dr. Marla Buchanan, an associate professor in Counselling Psychology at UBC, is my supervisor and can also be reached to answer any questions you have about the study. I would like to meet with both of you, at your convenience, in a confidential setting of your choice. If you would like to share your stories, I would love to listen. Please e-mail or telephone Niki if you are interested in participating.

Sincerely,

Niki Paley

E-mail: [REDACTED]

Telephone: [REDACTED]

Appendix C:

Screening Interview

“Thank you for your interest in my project. I would like to give you some details about the study, and then if you’re interested, I can ask you a few questions to figure out if you are eligible. Does this sound okay?”

“The goal of the study is to better understand how couples cope with having a child in pediatric palliative care and the transition into bereavement. I’d like to find out about individual and joint coping processes, how married partners accommodate one another’s coping, and, generally, how couples are able to remain intact during such a stressful and emotional time. To accomplish this I will be conducting in-depth interviews with couples where I will invite story-telling.

“Do you have any questions?”

“We will schedule a visit that will be convenient for both you and your partner and the interviews will last about 1.5 hours. About a month after the interview, I will send you transcripts as well as the story I have written based on what the narrative you will have shared with me.”

“Does this sound like something you both would be interested in?”

If YES—“That’s great. I’d like to ask you some questions now to get a sense of your experience and background and also to determine your eligibility for the study.”

If NO—“May I ask why? Thank you so much for your time and energy.”

Name: _____

Gender: _____

Home phone number: _____

E-mail: _____

Marital status (how long they have been married) _____

When did child die? (needs to be at least 1 year ago) _____

Name/age of child _____

Did they receive palliative care? _____

What got you interested in study? _____

Are both you and your partner okay with being interviewed and sharing your story as a couple? _____

Details/Notes:

“You might want to spend some time before we meet reflecting on your experiences as a couple coping with _____’s illness and death before we meet. It might be helpful for you to write about it or talk about it or even just spend some time thinking about your story as a couple.”

Appendix D:

Consent Form

Participant Consent Form

Title: Partners in Grief: Couples' Narratives of the Transition from Pediatric Palliative Care Into Bereavement

Principal Investigator: Dr. Marla Buchanan, Department of Educational and Counselling Psychology, and Special Education, (604) 822-4625.

Co-investigator: Niki Paley, Department of Educational and Counselling Psychology, and Special Education, UBC, (604) 250-0732. This research is being conducted as part of the thesis requirement for a Masters degree in Counselling Psychology.

Purpose:

I invite you to participate in a study on bereaved couples who have lost a son or daughter to a life-limiting illness. This is an area that deserves more attention and research as little is known about couples who have transitioned from pediatric palliative care into bereavement and your participation is greatly needed and appreciated. The purpose of my study is to document, describe, and understand the lived experiences of couples who have stayed together throughout their child's illness and now in the journey of bereavement. It is expected that the stories emerging from the study will lead to a better understanding of couples who have endured this type of loss and that other couples might benefit from these types of learnings.

You have been selected to participate because of your relevant experiences.

Study Procedures:

If you choose to participate in this study, you and your married partner will be interviewed together for about 1.5 hours. After the interviews have been transcribed, I will send back the transcriptions and your story to have you verify that the stories are accurate. In total, you will be committing about 4 hours to this research.

The interviews will be audio-taped, with your consent, and will be used for the interviewer's purposes only. The interview questions concern how you have coped as a couple, how you prepared for you son or daughter's death, and how you have managed this journey together.

Confidentiality:

The interviews are confidential and the raw data (audiotapes and transcriptions) will be reviewed only by me and my supervisor, Dr. Marla Buchanan, and will be kept in a locked filing cabinet for 5 years, following the research interview, and will then be destroyed. All documents will be identified only by a code number. To protect your anonymity, pseudonyms will be used when reporting the findings. If you wish to omit some aspect of the interview after we have met, I will honor that request. About a month after the interview, you will receive the transcript from the interview as well as your couples' narrative written by me. At that point, you will be able to verify that the narratives and transcripts are accurate and you may choose to change, add, or omit sections of your story.

Benefits:

You will not receive anything monetarily for participating but you might find that telling your story is beneficial to yourself and your partner.

Risks:

There is some minimal risk involved in this study. As the research topic is very personal, it may arouse strong feelings, such as nostalgia or sadness when speaking about your loss. If you feel any question is too personal, or you feel distressed during the interview, you are free to refrain from answering.

I am providing a list of counselling services that you might want to use in the case that the interviews bring up emotions and thoughts you want to process with a trained counsellor (see list with attached telephone numbers). You may also speak with Dr. Marla Buchanan (604-822-4625), a counselling professional, who has experience working with people dealing with grief and loss.

Contact for information about the study:

If you have any questions or desire further information with respect to this study, you may contact Dr. Marla Buchanan at 604-822-4625 or marla.buchanan@ubc.ca or Niki Paley at 604-228-1257 or npaley@telus.net.

Contact for concerns of rights for research subjects:

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.

Consent:

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from this study at any time without any negative

consequences. Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

Signature: _____

Date: _____

Appendix E: Interview Guide

Orientating interview question:

I'm interested in hearing about how as a couple you coped with having a child diagnosed with a serious illness and then learning that your son or daughter would be receiving palliative care and would eventually die from the disease. I also would like to hear about how you're doing now as a couple. I expect that you each have your individual stories and that this has been a complex experience. I really would like to hear about and understand your story as a couple, and as individuals, as fully as possible. There might be times when I ask you more about a specific situation and you can always choose to not answer a question or choose to stop the interview. This is your choice about what you wish to share. Maybe we can start at a time before your child was diagnosed, so that I can get a sense of your story as a couple, then we can go from there.

Main interview question:

“How have you coped as a couple with the transition from having an ill child receiving palliative care to being bereaved?”

Possible facilitating questions:

1. Before the diagnosis

- What was life like before the diagnosis?
- What was it like when your child was diagnosed?

2. Pediatric Palliative Care

- How did you deal with the news that no more curative treatment would be given?
- How did you prepare for your child's death together?
- What were some of your conversations?

3. Bereavement

- Have there been any moments where you've noticed that you've changed as a couple or individually in positive ways because of this experience? What have some of those changes been?
- How have you accommodated one another's coping styles?
- What is different about how you view life now—your relationships with each other and others, the world, etc.?
- What are some of “life lessons” or “life truths” that you have come to together as a result of your child's death?
- *Has intimacy been a challenging part of your relationship or has nothing changed in that area? Has it improved?

*These questions were added after my interview with Don and Christine after Christine emphatically expressed that this was an area in their relationship that became difficult and that I should ask the other couples about it.

Version 7/20/2006

Appendix F:

Resource List

BEREAVEMENT SUPPORT RESOURCES

British Columbia Bereavement Helpline

This is a helpline for referral and support. They can help you find local grief and counselling services to meet your specific needs.

Telephone: 604-738-9950 Toll Free: 1-877-779-2223

Living Through Loss Counselling Society (LTLC)

LTLC has a drop-in group for people who have issues related to loss through death. These sessions focus on sharing experiences, learning about the reaction to grief and loss, and coping mechanisms. The sessions take place Wednesday afternoons from 2:30 – 4:00 p.m. The sessions are free but donations are accepted.

Where: #210 1847 - West Broadway, Vancouver

Telephone: 604-873-5013

e-mail: ~~ltlc@ltd.com~~

Website:

<http://www.ltlc.bc.ca/>