When a child dies: The experience of families during the first year of bereavement as seen through their weblog entries

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Dedication

This dissertation is dedicated to the memory of the 10 beautiful children in this

study, and to their families who love and miss them.

Abstract

The study of CaringBridge weblog entries, written by10 bereaved families during the first year after their child's death from cancer, were analyzed for meaning of the experience using von Mannen's lifeworld existential as a framework: lived space, lived time, lived body, and lived other. In unscripted, real time journaling, families described their grief and the strategies employed to maintain connectedness to the deceased child: creating special places where they could feel close to the child (lived space); reflecting on time past, mourning the loss of future, and experiencing the firsts/lasts without the child (lived time); regarding metaphysical signs as messages from the child (lived other); and acknowledging their grief as a family (lived body). The results provide information to help health care professionals anticipate what families may need during the first year of bereavement and to guide intervention during that time.

Keywords: Family, family grief, family bereavement, weblog, diary, death of child, cancer.

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Chapter One: Introduction to the Study

The death of a child has been described as a traumatic and often overwhelming event for the family. It not only represents a permanent physical separation from the child, it is also seen as a loss of future hopes, dreams, and expectations (Rando, 2000). The loss of a child brings a variety of emotions and physical manifestations, including anxiety, pain, depression, and grief (Stroebe, Schut, & Stroebe, 2007;Moore, Gilliss, & Martinson, 1988; Znoj & Keller, 2002).

For parents who have experienced the death of a child, the resulting grief can be manifest in intense emotional, physical, psychological, and spiritual responses; responses that can last weeks, months, years, or may never go away. The intensity of this grief can impact individual physical and mental health as well as the marital relationship.

The purpose of this study

The purpose of this study was to describe the meaning that families give to the experience of the death of a child due to cancer. Specifically, this study sought to answer the question: *what is the experience for a family during the time immediately after the death of the child and continuing for one year, as recorded in their weblog entries?*

Clarification of terms

To provide clarity for the research study, the following operational definitions were used:

Family in this study refers to the parents and siblings of the deceased child and any others considered by the family to be a part of the family.

Family Bereavement is the period of mourning that exists after the death of a child. It encompasses not only grief, but also the rituals associated with the death.

Family Grief is a response to loss, in this case the loss of a child. This response is typically multi-dimensional and unique to those who are experiencing it. For grief following loss to occur, there must be some attachment to that which was lost (i.e., the deceased child).

A **diary** is a personal reflection of life and the world as well as life in the world. Generally written by one author, diary entries record events, perceptions, feelings, etc., experienced at the time that they occur.

A **Weblog** is a website which contains regularly recorded journal or diary entries, usually by one author. It is often called a "blog" for short. In this study, the weblogs were derived from the sponsored website CaringBridge.

Blogging is the act of recording one's thoughts and feelings into an online diary; writing in the web log.

Family grief and bereavement

The backdrop for this study is family systems theory, which recognizes the family as a complex social system made up of individuals (Whitechurch & Constantine, 2009). Within the family system are units (members), boundaries, and relationships (e.g., mother-child or marital relationship). The interaction of the units or subsystems (e.g.,

dyad of mother-child) occurs within the boundary of the system, which is created around that collective group. Thus the boundary defines the system and serves as an interface for continuous interaction between that system and the outside world, (Broderick & Smith, 1979; Whitechurch and Constantine, 2009). Every family system possesses a boundary, often viewed as a metaphysical concept or membrane that separates the family (within) from the external world. Each family's boundary has a certain amount of permeability for the exchange of information with other systems. In simple terms, this boundary can be open or closed. Those families with open boundaries will have a greater exchange of energy and information with the world; those with closed boundaries will have less exchange (or even none at all) (Harbaugh, Tomlinson, & Kirschbaum, 2004; Tomlinson & Harbaugh, 2004;Tomlinson, Swiggum, & Harbaugh, 1999].

When there is a loss of a family member, each member of the family experiences grief individually, but the subsequent interactions within the family and between the family members impact the family system (Murray, 2000). In other words, the grief experienced by individuals influences the family's grief experience and the family's grief influences the grief experienced by individual members. Moreover, the grief process can influence the function of the family as a whole maintaining its social obligations.

Family health is often described in the literature in relation to the family system (Friedman, 1998; Meiers, 2002; Whitechurch & Constantine, 2009). While there is no absolute definition for family health, the Family Health System (Anderson & Tomlinson, 1992; Tomlinson, 2001) and the Family Health Systems Model serve as useful resources to look at family health from a systems perspective. Specifically, the Family Health

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Systems Model (Tomlinson, 2001, Tomlinson, Peden-McAlpine, Sherman, 2011) identifies four domains of family dynamic related to health care: Integrity Maintenance; Coping; Health and Developmental Transitions; and Health-Related Interactions. The goal is to help families achieve balance within the four domains. If there is a significant health event that impacts this balance, the resulting disequilibrium can impact the function of the family in meeting crisis. One such event is the death of a child.

While all four domains of the FHS model have relevance to the current study, the integrity realm is particularly important. Family integrity manifests itself through connectedness of the members; families employ self-regulating strategies to maintain their integrity as a unit with its own metaphysical boundary (Tomlinson, et al., 2011). When there is a death of a family member, the physical connection is severed and the integrity of the family as a system is disrupted with the metaphysical boundary missing an essential member. When that death is a child, the impact can be especially difficult; the family as a whole is forever changed.

Studies have focused on bereavement following the death of a child from different points of view. For example, some investigations have focused on mothers (Davies, 2005; Davies et al, 1998; Milo (1997); Laakso & Pannonen-Illmonen, 2001; and Braun & Berg 1994) while others look at bereavement from the father's perspective (Ware & Raval, 2007; Davies et al, 2004). Still others addressed the dyadic relationship of father and mother (Gilbert, 1989; Schwab, 1996; Steele, 2000). While Schwab found that mothers experienced more intense grief than fathers, others found that fathers tended to grieve differently than mothers (Seecharan, Andresen, Norris, & Toce, 2004).

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The circumstances surrounding a child's death have also been viewed in terms of the parent's and the family's bereavement. Murphy, Johnson, Wu, Fan, & Lohan (2003) explored the experience of mothers and fathers after the death of a child due to suicide, homicide, or accident. Parents studied by Schwab (1996) had experienced the death of a child due to stillbirth, cancer, suicide, murder, AIDS, SIDS, accident, or other acute illness. While all parents experienced grief, their responses and intensity varied with relation to the events surrounding their child's death (Murphy, et al, 2003; Schwab, 1996).

Most investigators agree that recall of the experience remains vivid regardless of the time elapsed since the child's death, the age of the child at the time he/she died, or the cause of the child's death (Bohannon, 1990; McClowry, Davies, Kulenkamp, & Martinson, 1987).

While some parents choose to deal with the death of their child in private, others seek out the support of others. The sources of support most often identified by bereaved parents included family, friends, and their faith (Arnold & Gemma, 2008). More formal venues for support include bereavement groups such as Candlelighters, which served as a source of participants for individual studies on bereavement (Braun & Berg, 1994; Wheeler, 1994).

Need for this study

Most studies have examined individual and family bereavement from a post-hoc view after the death of a child. Research methods used in these studies have included surveys, interviews, or a combination of surveys and interviews (Seecharan, Andresen,

Norris, & Toce, 2004; Davies, et al, 1998, Laakso & Paunonen-Ilmonen, 2001), asking the participants to reflect back or recall events, feelings, and emotions experienced at an earlier time. This post-hoc view, while serving as a source for research, does not fully capture the experience of grief and bereavement as it was occurring for the participants. This study is needed because it provides additional information about family grief and bereavement in real time through the weblog (journal) entries of key family informants. By examining the family's bereavement through this lens, the data provided by the informants is a true reflection of what they are experiencing *at that time*.

Research approach

The nature of grief is by definition an experiential process that many research methods will not uncover. Phenomenology is a qualitative research method that specifically focuses on the lived experiences of human beings. It is a study of the *lifeworld*, that is, the world as one experiences it (van Manen, 1997), the aim of which is to gain a deeper understanding of one's everyday experiences. Specifically in this study, its use provides structure for the analysis of family weblogs as representations of the family's grief experience.

Historically, there are two distinct approaches to phenomenological research, descriptive and interpretive phenomenology. Descriptive phenomenology is based on the work of Husserl (1935/1965) and seeks to know the essence of the phenomenon studied through the "lived experience" of the participant. Interpretive phenomenology looks at the individual's relationship to the world; it is the interpretation of the individual's

experience in the world and the meanings they make of the experience (Heidegger, 1953/1966).

The chosen phenomenological method for the study was based on van Manen's approach, which takes from both Husserl and Heidegger and combines them as a study of existential meanings. It is the interpretation of the phenomenon from the individual's perspective. van Manen describes phenomenology as a unique, reflective discipline which begins in the lifeworld. However, he does not fully define phenomenology because he believes it is only understood when one "actually does it" (van Manen, 1997, p. 8).

The aim of phenomenology, according to van Manen, is to "transform lived experience into a textual expression of its essence" (p. 36). Based on Merleau-Ponty's (1962) description, *essence* is the linguistic description that one gives to a phenomenon. It is through the study of the lived experiences of others that allows the researcher to capture the meaning in order to more fully understand the phenomenon of concern.

Significance for nursing and health care of families

Whether being asked to describe the death of a child shortly after it had occurred or years later, bereaved parents are able to vividly express their recall of feelings, emotions, and perceptions of the event (citation). However, as discussed earlier, post hoc reflections at best provide only some insight into what parents experience after their child has died. Unfortunately, most of what health professionals have been taught about family bereavement is based on studies in which the data about the family's post-hoc experience

is gathered some time after the death of the child. Although these descriptions about the child's death are strong, there are limited studies which provide a mechanism of validation of the day to day experience for the family. There are practical and ethical reasons which have made studies such as this one difficult. Intrusion into the lives of families going through the death of their child and subsequent period of bereavement could be disruptive and may be unethical, especially for families at risk. .

To date, there have been no studies published that look at family bereavement prospectively through the lens of the weblog. With the advent of Caring Bridge, weblog entries, recorded in real time by the weblog author(s) of families experiencing diagnoses and eventual death of their child gave the opportunity to study prospectively.   By examining the family's weblog entries, the investigator believed that one would be able to get a sense of the family's experience of bereavement while the experience is ongoing.

Chapter Two: Review of the related literature

A systematic review of the literature related to families, grief and bereavement was conducted to explore existing knowledge about grief and bereavement for families. The question driving the search was *"How is grief and/or bereavement experienced and/or described in the first year following the death of a child?"*

Databases utilized included CINAHL, Medline, Psych info, Social Work Abstracts, Proquest Nursing, and Proquest Psychology. Initial terms searched included Grief, Loss, Mourning, Bereavement, Death, Dying, Family, Parent, Mother, Father, and Child. After that data was obtained, a second search was done combining two or more terms and the resulting data was then examined at length. Additional words and phrases were searched, including anticipatory, anticipatory grief, sorrow, end-of-life, life-threatening illness, life-limiting illness, cancer, critical, hospice, palliative care and terminal illness. These were again combined with the primary terms, which yielded additional citations for review.

To ensure consistency and thoroughness, Whittemore's criteria for quality research was used in the analysis of the existing literature (2005). The investigator felt it important to employ a consistent measure of quality when reviewing the studies to ensure that the literature is sound, the methods valid and reliable, and that the results are applicable to the current study.

In studying the literature, it became apparent that in order to focus the review on the research question, some studies would need to be ruled out. Thus, the literature that

dealt with families grieving the loss of children under the age of 20 was included; studies

addressing the death of children over the age of 21 (i.e., adult children) were therefore

excluded. Because this was a study of death due to cancer, the choice was made to

remove studies that exclusively addressed bereavement after sudden death of a child due

to SIDS, accident, injury, or murder. As individual studies were reviewed, additional

research was explored from their reference lists. Other resources reviewed included peer-

reviewed anthologies and books.

The majority of studies discussed here implemented some type of qualitative

method of inquiry; the rich narrative descriptions provided by the informants highlight

the meanings and patterns of association related to the phenomenon of grief.

Grief/Bereavement Studies

Most studies regarding grief and bereavement focus on individuals or dyadic

relationships; though families were acknowledged few include the whole family system.

This is a gap in the literature, and the relationship to understanding family grief. Bowlby

(1969, 1975, 1980) is perhaps most recognized for his work with parental emotional ties

(e.g., attachment), but equally important is Bowlby's work related to parental grief, an

early recognition of the importance of the family in grief and bereavement. Bowlby

believed that the parent of the child who has died experiences four phases of mourning:

numbing; disbelief/attempt to reverse outcome; disorganization; and reorganization.

(Bowlby, 1980, 116-122) According to Bowlby, at the time the diagnosis is made, the

parent enters a period of mourning. In the initial phase of what Bowlby called numbing,

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the parent experiences what can be likened to a state of shock; the whole situation feels unreal. Bowlby believed that anger was also a part of this phase, usually directed at the one who delivered the diagnosis. Next the parent moves into a phase of disbelief in which the parent may challenge the diagnosis and question the eventuality of death. This disbelief can persist for many months even after the child has died. During the phase of disbelief, there may be intentional denial of the terminal diagnosis on the part of the parent. Often there can be anger during this phase but that may wane as the parent begins to accept the diagnosis. The parent may also seek out alternative treatments and opinions in an attempt to reverse the finality of the diagnosis. This can be so time consuming that all other daily activity is suspended. There may also be self-blame on the part of the parent for their child's illness. In the phase of disorganization, the child's illness progresses and hope begins to fade. In reorganization, the final phase is reached; there is an adjustment to new roles, new relationships, and acceptance of the death.

One of the beliefs held by Bowlby regarding mourning was that how well or poorly the mourning proceeds will impact the relationship between the parents. Bowlby believed that parents needed to mourn together, moving through the phases of mourning with each other, in order to have a positive outcome of the mourning. Failure to mourn together could lead to marital discord and/or mental health issues for individual family members.

While it may be true that the grief experience for the parents impacts the relationship, this idea that mourning together and moving through the phases with each other needs to be tempered with more recent grief and bereavement studies, which

indicate that couples grieve differently, their grief experience is manifested differently, and that it changes over time. This is addressed later in this chapter.

Another often cited in the grief/bereavement literature is Elizabeth Kübler-Ross's Stages of Grief (1969). Kübler-Ross brought the concept of grief and grieving out into the open, inviting conversation and study about how individuals deal with death and dying. Because she does not focus on families, this open dialogue about death and dying is the primary relevance to the present study, as well as her well known contribution to the Stage Theory of Grief that has some application to family response.

Perhaps because of the time in which it was written, many interpreted Kübler-Ross' stages progressing through an orderly, linear fashion (although this was not her intent). The grief process was viewed as having a beginning and an end. (Kübler-Ross, 1969) Since then, it has been recognized that individuals move in and out of the stages over time and that movement is random. Kübler-Ross herself stated, for example, that after initial denial, the individual tends to go back into denial from time to time as they deal with their impending death (Kübler-Ross, 1969, p. 35), trends that Bowlby later saw in families. Kübler-Ross also emphasized that grief takes time.

Kübler-Ross's work contributed positively to an open dialogue about death, dying, and grief. However, the idea that grief was to be resolved within a determined time frame became the standard expectation. As a result, interventions often focused on the resolution of the grief in order that they return to their pre-grief state or "normal".

In a landmark nursing study, Miles (1984) proposed a model for parental grief which divides the grief process into three stages: *numbness and shock, intense grief, and*

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reorganization. Although Miles believed that grief is a unique, individualized experience, the three stages represent a way to broadly describe what occurs for the person as they grieve. At the onset of phase 1, numbness and shock, the death of the child has taken place. The parent experiences feelings of disbelief, denial, and a sense that everything is unreal. The shock serves as a cushion to the full impact of the death and subsequent grief; it gives the person time to process the reality of what has happened. For some, the shock can immobilize the parent into a state of being unable to function or make decisions. For others, the shock can create a state of numbness to the point of showing no emotion or reaction to the death. For the parent who has witnessed the long decline and suffering of the child prior to death, there may be feelings of relief along with the numbness and shock.

Phase II is a period of intense grief that can begin anywhere from hours to weeks after the death of the child. Parents reported episodes of pain, panic, and depression. Parents also experienced reactions such as yearning and helplessness (with resulting anger or guilt), demonstrated physical symptoms and behavioral changes, and conveyed a need to search for the meaning of the child's death. While most of these reactions were self-evident, further explanation of yearning highlights the intensity of the parent's emotional state. During yearning, the parent longs for the deceased child and this longing can be evidenced by being drawn to places associated with the child (e.g., the child's room), hearing the child's cry or having dreams of the child. They may also become preoccupied with memories of the deceased child.

In phase III, or reorganization, the parent takes a new interest in life and is able to speak about the prospect of moving forward. Miles emphasized that reorganization is not recovery of grief; parents state they never recover from the loss. A parent may continue to experience the pain felt at the time of the loss long after the child's death; this pain can be triggered by an event or a memory.

Working through the three phases of grief takes time and that time varies for every person. Contrary to Bowlby's belief that parents should grieve together, Miles (1984) emphasized that parents grieve differently and at different times. This grieving out of step is to be expected and considered to be normal. Indeed, when comparing grief scores for mothers and fathers using the Grief Experience Inventory, Schwab (1996) found mothers scored higher on several categories, including Despair, Anger/Hostility, Guilt, Loss of control, and Physical Symptoms. This further illustrates that parents grieve differently.

For some grieving the loss of a child begins even before the child has died. Fulton and Fulton (1971) first described this phenomenon as anticipatory grief, a way to expedite grief resolution. Rando (2000) further developed the concept of anticipatory mourning, citing a distinct difference between anticipatory grief and anticipatory mourning. According to Rando, grief as the reaction one experiences to a perceived loss; mourning includes not only grief, but also the actions an individual employs to cope with, adapt to, and accommodate the loss. She described these actions as having six dimensions; *perspective, time focus, influencing factors, major sources of adaptation demands, generic operations, and contextual levels*. (Rando, 2000, 51). Several of these

dimensions had subsets, further delineating the dynamics influencing anticipatory

mourning. According to Rando, anticipatory mourning does not just focus on the

anticipated death; it also includes the past and the future.

There does not seem to be consensus regarding the importance of the concept of

anticipatory grieving. Rando herself acknowledged that there are studies which support

anticipatory mourning while others refute the benefits of anticipatory mourning (2000).

Some degree of anticipatory mourning is believed to help move the individual to

acceptance of the loss. Too much anticipatory mourning can cause premature

detachment while not enough can cause a marked increase in post-death grief. Rando,

however, believed that those working with individuals and families during the time

before death need to recognize anticipatory grief and mourning when it occurs and

intervene appropriately (Rando, 2000).

Others have described anticipatory mourning as something that often begins even

before the diagnosis of terminal illness (Ashton & Ashton, 2000). A parent who

perceives something wrong with their child's health may go through early mourning as

they ponder the possible outcomes of a yet unknown diagnosis. When the parent learns

of the terminal diagnosis, the reactions experienced are often similar to the reactions of

parents who learn of the sudden death of their child. There is a state of shock and

disbelief initially, followed by acute grief. During this period of anticipatory mourning

the parent grieves not only the present, but also the past (e.g., what if I had brought him

in sooner?) and the future (e.g., my child will not graduate from high school).

Anticipatory mourning in parents who experienced the death of their hospitalized child was also explored by Rini & Loriz (2007). Specifically, the authors sought to discover whether or not parents had experienced anticipatory mourning and if they had, what factors were helpful or not helpful. Parents who felt they were given detailed, realistic information from the health care team felt they were better able to make decisions about their child's treatment (including the decision to stop). Parents wanted honest information about their child's dying. Many parents interviewed knew that their child was dying and had begun to mourn the loss before the actual death of the child. For those parents who did not know their child was dying, when the death occurred they felt unprepared.

Findings in a Finnish study present a different view that not all anticipatory grief experiences are positive. For eight fathers who had lost a child under the age of three, anticipatory grief was seen as inhibiting grieving once the child had died. Aho, Tarkka, Åstedt-Kurki, and Kaunonen (2006) described fathers' grief and the changes that their child's death brought to their lives. Fathers expressed feeling powerless to protect their child from death, vacillating between hope and despair as their child's condition improved or declined. These fathers expressed disbelief when told of their child's prognosis and felt they had no control over their own lives, describing themselves as mentally exhausted. Witnessing their child's pain and suffering, the fathers had moments where they hoped for their child's death. Once the child had died, the fathers experienced a plethora of emotions and physical sensations as they grieved their lost child.

In summary, some researchers believed that there may be times when the grief experience of individuals and families is less intense because there has been some early grief work done prior to the actual death of the family member. For some, anticipatory grieving was helpful; for others, anticipatory grieving had a negative impact on the grief they experienced after the child had died.

In the 1980's, there appeared to be a shift in the literature that from grief resolution to a recognition that grief remains present but changes over time. Put simply, grief changes but it does not go away.

There were several studies that focused specifically on bereavement of parents following the death of a child. Some studies examined grieving mothers (Davies, 2005; Davies et al, 1998; Milo, 1997; Laakso & Pannonen-Illmonen, 2001; and Braun & Berg 1994) while others explored grieving from the father's perspective (Ware & Raval, 2007; Davies et al, 2004). Some studies addressed the dyadic relationship of father and mother (Steele, 2000; Gilbert, 1989). Schwab (1996) found that mothers experienced more intense grief than fathers. Others found that fathers tended to grieve differently than mothers (Seecharan, Andresen, Norris, & Toce, 2004).

The circumstances surrounding a child's death and the resulting grief responses were also examined. Murphy, Johnson, Wu, Fan, & Lohan (2003) studied mothers and fathers after the death of a child due to suicide, homicide, or accident.   Parents studied by Schwab (1996) had experienced the death of a child due to stillbirth, cancer, suicide, murder, AIDS, SIDS, accident, or other acute illness. In both studies, parents whose

child had a more sudden, unexpected death, experienced grief/bereavement that was often more intense and the emotional impact more severe (Murphy, et al, 2003; Schwab, 1996).

The majority of the studies of family bereavement used post-hoc methods including surveys, interviews, or a combination of these methods (Davies, et al, 1998, Laakso & Paunonen-Ilmonen, 2001; Seecharan, Andresen, Norris, & Toce, 2004). While providing important contributions to current understanding of grief, data were based on the participant's recall of past events.

Recollection of the time surrounding the child's death remains vivid to the one bereaved regardless of the time that elapsed since the child's death, the age of the child at the time he/she died, and the cause of the child's death (Bohannon, 1990; McClowry, Davies, Kulenkamp, & Martinson, 1987). For example, Dyregrov & Dyregrov, (1999) studied parents who experienced the death of a child due to SIDS; two-thirds of those parents still felt the impact of the child's death 12-15 years after the event. Despite this ability to recall the death of the child, memories of events during the year following the death were not as strong. This lends to the argument for the present study, which looks at family grief as it is occurring.

While many of the studies above were described as family studies, they really looked at the grief experienced by individuals and dyadic relationships within the family. This is in part due to time when some of the studies were done, and in part due to the access to the full family by the investigators .Because the grief experience for family members impacts the family grief experience, the next section will highlight some of those studies and their findings.

One of the few true family studies examined family grief 7-9 years after their child had died from cancer (McClowry, Davies, Kulenkamp, and Martinson, 1987). Family members were still experiencing pain and loss 7-9 years after the death of the child. Additionally, instead of talking about letting go of the child, family members described their lives as having an empty space where the child had once been. Family members who appeared to have resolved their grief no longer had an empty space: their memories of events and the lost child had faded.. Filling the emptiness was experienced by a second group of family members. These individuals filled the empty space by either becoming very busy or by filling their time with other problems. Families who kept the connection were busy too, but rather than these activities replacing the energy spent on grief, there was a continued sense of grief along with the activities. Family members described their pain and loss as being a part of their lives, although this gradually decreased in intensity over time.

Grief behaviors and rituals

Rituals are important to individuals who are grieving (Castle & Phillips, 2003; MacConville, 2010). Some choose to create memorials or spaces to honor the deceased child; others will preserve existing spaces such as the child's bedroom (Gudmondsdottir & Chesla, 2006). Additionally, photographs aid families as they grieve, serving as a durable biography of the child's life (Riches & Dawson, 1998).

Who then, decides which grief behaviors and rituals are "normal"? In order to gain a better understanding of "normal" grief, Demi and Miles (1987) conducted a

modified Delphi study in which 34 grief experts were invited to identify grief behaviors

that were within the range of normal and those that were outside the range of normal.

(The descriptor "abnormal" was not used due to the negative connotations associated

with it.) Participants were asked to assign a time designation to 33 terms that would

indicate the shift from normal to out of the range of normal. Time intervals were 1

month, 6 months, 12 months, 24 months, and 60 months post bereavement. There were

variations by the participants as to designation of the shift from normal to out of the range

of normal; however the authors observed an increase in the number of terms moving to

the latter category as time from bereavement increased. In other words, the longer the

period of time from initial onset of grief, the more likely the behaviors were to be viewed

by the experts as out of the range of normal.

The authors did not solicit general belief statements from the participants,

however they were provided with three affirmations of beliefs by the majority of the

participants. The first was that the bereaved individual should be back to a previous level

of functioning within 2-3 years. The second belief to be affirmed was that in some cases

grief may never come to an end and that is acceptable. Finally, if grief has been resolved,

the bereaved person should be able to talk about the lost loved one with ease. Beliefs that

were rejected by the majority include the idea that all grief responses are normal; that

grief out of the range of normal is evidence of psychopathology; that grief is always

healthy; and that disabling grief should decrease in 4-9 months following the loss. (Demi

and Miles, 1987, 407). While the results of this study are more than 20 years old, this is

still an important work as many definitions of grief continue to be based on descriptive behaviors rather than the process itself.

Parental differences by gender

The death of a child has been described by many parents as going against the natural order of the world. Parents see themselves growing to an old age and dying before their children, not outliving their children. When a child dies, it affects not only the parents as individuals, but also the parents as a couple.

Part of working through grief, saying goodbye to the child at the time of death (to the parent's satisfaction) is viewed as critically important by parents. In a longitudinal study, Winjgaards-deMeij, L, Stroebe, M., Stroebe, W., Schut, H., Van Den Bout, J., Van Der Heijden, P.G.M., & Dijkstra, I (2008) interviewed and surveyed parents at 6, 13, and 20 months post the death of their child. Parents who said farewell had lower levels of grief than those parents who did not feel they had said goodbye.

Lifelong grief experienced by parents following the death of their child has been reported by others (Arnold and Gemma, 2008). These authors surveyed bereaved parents to examine grief over a lifetime. The results supported the belief that parental grief is complex and that the process of grieving does not have an end and the explicit memory of the child's death remained vivid for the parents. The parents described their grief as existing below the surface but always present. For example, parents felt that when others chose not to talk about the deceased child, there was a resulting feeling of being cut off from sources of support. Parents employed several strategies to feel connected to their

deceased child, including sensate information, rituals and images. One thing the authors emphasized: parents want to talk about their deceased children and about the grief they are experiencing.

To summarize, whether being asked to recall the death of a child shortly after it had occurred or years later, grieving parents were able to vividly describe their feelings, emotions, and perceptions of the event. Grieving takes longer than a year. Once the parent is able to achieve some level of resolution, they report a decrease in their grief. When couples grieve, it may not occur in a synchronous fashion. This can be a source of conflict for the parents.

The grief experience of mothers has been described in the literature as very emotional and intense. In international study of the experiences of 21 mothers whose child died of cancer, Davies, Devau, deVeber, Howell, Martinson, Papadatou, Pask, and Stevens (1998) interviewed mothers about their experience during the last month of their child's life and the time following the child's death. Mothers first answered questions about the family constellation, followed by questions about the child's disease and mother's reaction to learning about the terminal illness. Mothers were then asked about the last month of the child's life and the care the child received at that time. The final portion of the interview focused on mother's bereavement, including her perceptions of her relationships with and the coping done by other family members.

In the bereavement phase, mothers reported difficulty in dealing with the quietness of the home and missing the physical presence of the deceased child. Mothers described the emotional pain and loss of joy since the child's death and also experiencing

physical symptoms such as insomnia. Mothers identified what gave them comfort, largely

from supportive relationships from family, professionals, and friends. Since the death of

the child, mothers perceived that the fathers were having the toughest time dealing with

the death.

In a similar study, Laakso and Paunonen-Ilmonen (2001) interviewed 50 Finnish

mothers who had lost a child under the age of 7. As mothers reflected on their

experience, they described that during their child's illness phase, their feelings ranged

from hope to despair and that despite a sense of the impending death, the mothers were

still surprised when the death occurred. When the child died these mothers, like the

previous study, experienced physical responses (e.g., pain and fatigue), psychological

responses(e.g., depression and anger) and loneliness.

When asked to reflect on their experience during the time before, during, and

immediately after the death of their child, mothers were able to articulate what they

needed (Davies, 2005**).** Mothers wanted *time* and *private space* to spend time with their

dying child.   Mothers also wanted *time* and *private space* to be with their child's body

after the child had died. Mothers who had no access to hospice services wanted to keep

their dying child at home rather than having them hospitalized; mothers whose children

died in the hospital felt the experience was limited by hospital rules. Further, mothers

who were able to participate in the care of their dying child felt they had more positive

memories as a result.

Rather than interview bereaved mothers individually, Saiki-Craighill (2001) opted

for a support group setting. Twenty-four Japanese mothers who had lost a child to cancer

in the last year shared the experience of treatment leading up to the death of the child, the

child's death, the funeral, and how things were going for the family since the child's

death. The author described three themes that emerged from the analysis: a numbing of

emotions, the grieving period, and moving out of depression (Saiki-Craighill, 2001, 261-

265). At the time of the child's death, mothers experienced a period of feeling numb.

Many described the time of the child's funeral as being unreal, and that they used the

funeral as a way to avoid the reality that their child had died instead of a way to help

them accept the death. This period of feeling numb was short lived; after the funeral

activity of daily life resumed and the mothers had to face the reality that the child had

died. Mothers described an awareness that their child was no longer physically present

but that it took a while to realize that they were gone forever. After this realization,

mothers moved into a period of grieving. Depression was a common emotion

experienced by all of the mothers as they blamed themselves for the child's death. Most

chose to withdraw from contact with others, including family. Mothers tried to hide their

sadness from everyone else, yet felt angry inside when they didn't recognize the façade

they had created. Mothers felt that they needed to recognize that the child's death had

meaning, which allowed them to move out of depression. Some felt that support group

participation helped them to do just that. They moved beyond their depression and

rejoined activities of daily life, but they also noted that their sadness did not change.

Talking about their child and the loss experienced when a child dies helps

mothers to adjust to their new reality (Braun & Berg, 1994). Having someone listen

gave 10 bereaved mothers a sense that they were understood; this also helped them as

they created new meaning. The authors believed that the findings of this study indicated that individuals do not grieve through stages and then resolve their grief but rather that they adjust to a new reality in a world without their child.

Mothers are not the only members of the family who are grieving. To better understand the lived experience of fathers who had a child with a life limiting illness, Ware and Raval (2007), conducted a semi-structured interview with eight fathers. The events leading up to and including the diagnosis were vividly recalled by the fathers regardless of the amount of time that had passed. All talked about the subsequent emotional impact on their lives when they came to learn that their child had a life-limiting illness. They talked about being in shock and feeling grief and sadness. Once they had accepted the diagnosis, the fathers described ways in which they began to live with what had happened. They identified ways that helped them to feel they were taking control of the situation, including asking questions and seeking information about the diagnosis. The fathers talked about how men are different when it comes to coping with the reality that their child was dying; the fathers felt that men were not allowed to be emotional and that they were limited in their social support. Despite those feelings, the fathers did in fact want to talk about what was happening.

In another study that addressed the lived experience of 8 fathers whose children died 12-36 months earlier as the result of a life-limiting illness, fathers described the dying phase of their child's life as though fighting a mythical dragon (Davies, Gudmundsdottir, Worden, Orloff, Sumner, and Brenner 2004). In the end, the father did not slay the dragon but rather the dragon took the life of their child. Themes identified

involved the challenges faced as a battle: *battling uncertainty, battling responsibility, and battling the disruption of everyday life.* (Davies, et. al, 2004, 118-126) Fathers described how their work environment and their interactions with health professionals influenced their battle with the dragon. If the work environment was supportive and the interactions with health care professionals positive, it was easier to face the challenge of dealing with their child's dying.

The role of social support in grief

While some families choose to deal with the death of their child in private, others seek out the support of others. Arnold & Gemma (2008) found that the sources of support most often identified by bereaved parents included family, friends, and their faith. More formal venues for support include bereavement groups such as Candlelighters; these support groups have served as a source of participants for individual studies on bereavement (Braun & Berg, 1994; Wheeler, 1994). Interestingly, the majority of people will use their social support networks to help during the time of grieving rather than seek out formal support groups (Love, 2007).

Summary of the literature review

All of the literature reviewed described the death of a child as a powerful, traumatic, overwhelming event for the parents and that the resulting grief experienced by each is unique for that person. Grief is seen as a process that takes time; each person progresses through grief at their own rate. There are some who believe that grief should

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be resolved within the span of one to two years, while others acknowledge that grief may never have total resolution. Because the term resolution implies a recovery and moving on, more recent studies have described grief waning and the individual moving into a more adaptive response to the loss of the child. Parents relate their experiences of resuming their lives as a new normal in which the deceased child is gone, but not forgotten.

Chapter Three: Methodology

Phenomenological research explores the lived world experiences of everyday life. The structure of the meanings assigned to these events are described as four fundamental themes which are universally shared by all humans. Based on the work of Merleau-Ponty (1962), van Manen describes these four lifeworld existential themes, as *lived body, lived time, lived space*, and *lived other (*van Manen, 1997, pp 101-106).

Lived body refers to the corporeal being. We are always bodily in the world. When we encounter another human being, we first react to the physical presence. We both reveal and conceal things about ourselves in that interaction.

Lived time refers to subjective time, not clock time or objective time. Lived time refers to how we perceive time, which can speed up or slow down depending upon the experience. As human beings, our temporal makeup is of our past, our present, and our future. Our past includes our memories, which can at times influence our present experiences. Our future includes hopes and dreams, which also influence our present experiences.

Lived space includes the way we experience our surroundings or spatial dimensions of our world. Space can affect the way we feel based on its size, location, and previous experiences. Home is viewed as a special secure spatial experience, which influences our being. Examining lived space can reveal how we experience the affairs of our everyday life.

Lived other describes our relationship to others in the interpersonal space that we share. Included in these relationships are our sense of purpose or meaningfulness in life, our reason for living, and our relationship with God.

Van Manen asserts that these four life world existential themes are overlapping, can be differentiated but cannot be separated; they form our lifeworld view. However, when conducting phenomenological research, we can temporarily examine the existential as we search for meaning of the experience.

Diaries and research

Diaries or journals have long been used as a method of data collection (Bolger, Davis, & Rafaeli, 2004). They provide the researcher with a historical view (Rosenblatt, 1983), a validation of interventions (Morrison-Beedy, Carey, Feng, & Tu, 2008; Poppleton, Briner, & Kiefer, 2008; Werner, Molinari, Guyer, & Jenni, 2008;) or can be utilized as a self-help tool (Peng & Schoech, 2008;). Diaries can be either structured or unstructured (Cohen, Leviton, Isaacson, Tallia, & Crabtree, 2006). In structured diaries, the researcher dictates to the participant the topics to address for each entry; unstructured diaries are based on the ideas and experiences of the participant without any restriction on topic. Diary methods have included pencil and paper recordings, enhanced paper diaries in the form of a checklist, and through the use of hand-held or electronic data recording devices.

For the researcher, diaries are written records that give a voice to the personal experiences of others. These "documents of life" are valuable sources of information

because they are the recordings of important personal experiences for the writer made at or near the time of the event described (Alaszewski, 2006, p.44-45).

Diaries have been used to record daily life experiences by families. Kloos & Daly (2008) studied the effect of diaries maintained by families of patients who had undergone coronary artery bypass graft (CABG) surgery. In that study, the family spokesperson was given instructions to write in the diary daily about predefined topic areas and also any thoughts and feelings they experienced throughout the day. Although the participants were provided with guidelines for their diary entries, the themes that emerged from the content analysis on the thoughts and feelings section of the diary centered on the emotions of family members, observations about the patient, thoughts and feelings about the health care team, and aspects of spirituality. This disclosure of personal information showed that family informants want to share what they are experiencing during a stressful time.

Välimäki, Vehviläinen-Julkunen, & Pietilä, (2007) reviewed the diaries of caregivers with a family member with Alzheimer's disease. Caregivers were asked to keep a diary for two weeks and were given general instructions as to what they should focus their writing on, namely the description of their experience of caring for a loved one with Alzheimer's disease. Written instructions were also provided to the caregivers; these instructions outlined possible themes for their writing. Some diaries were returned with minimal content while others were quite extensive; all diaries revealed information about the caregiver's day to day experiences of caring for a family member with

Alzheimer's disease. Again, this showed a willingness to share their experiences by the family informants.

An advantage to diary writing is that it can facilitate the collection of sensitive information (Hookaway, 2008). A diary is recorded in "real time", that is, at the time the events, thoughts, and feelings have occurred. Because of the temporal nature of a diary, there is less chance of participant memory fading over time. These personal reflections of life events are rich with information about the individual's and/or the family's experience. Further, diary entries need not be recent in order to be studied Rosenblatt (1983), looked at 56 diaries written in the 1800's, providing a historical look at separation and loss for those who wrote the diaries. From the diary entries, Rosenblatt determined that the emotional experience of bereavement for persons in the past mirrored those studied in the present day. It is important to note that the diary entries were robust enough to be analyzed without additional validation by the diary authors; each entry was a true reflection of the author's experience at that time.

The Internet and the World Wide Web in research

The advent of the internet and world wide web has created additional methods for generating research such as teaching measures and online support groups (Anderson et. al, 2008; Barak, Hen, Boniel-Missim, & Shapira, 2008; Harrison, Barlow, & Williams, 2007). The internet has also been used for recruiting study participants, especially for topics that are sensitive such as AIDS research, addictions, and sexually transmitted diseases (Baer, Souroiu, & Koutsky, 2002; Koo & Skinner, 2005).

As the technology has grown, so has communication through the web. Individuals have instant access to others through e-mail, hosted web pages, online discussions, chat rooms, and more recently, weblogs. Suzuki & Beale (2006) looked at the personal web pages of teenagers with cancer. Analysis of the web page content provided a look into the life of a teen with cancer, including coping strategies used by the teen during treatment. Lasker, Sogolow, & Sharim (2005) reviewed the online chat postings of members of the Primary Biliary Cirrhosis Organization, in particular posts for the months of March and September 2003. Results showed that the primary reason for posting was biomedical in nature, especially for validation of knowledge.

The weblog or "blog" came online in the late 1990's (Cohen, 2006). Weblogs are websites that are based on a journal or diary style format. Unlike chat rooms or online discussions that contain written postings by many individuals in a public forum, weblogs are written by the blog owner.   If others wish to respond to a weblog entry, a separate section for posting typically exists.   Although a personal diary, the weblog entries that are posted are available for viewing by the public.

Each entry to the weblog is recorded by time and date; individual entries can be made as often as several per day to one per month (or longer). Traditional pen and paper diaries record events in chronological order with the first entry on page one, the second on page two, and so on. Weblogs record entries in reverse order, with the most recent always at the top.

Weblog use has steadily increased over the past 10 years. Since 2002, there have been 133 million weblog records indexed on the web (Technorati, 2008). There are

approximately 900,000 weblogs posted every day. The volume of weblogs available

serves as a great source for data collection, yet only a handful of studies looking at

weblogs have been published. The majority of the research on blogging has been done in

the information technology/computer science field, or by those in mass media

communications (Hookaway, 2008).

Chung and Kim (2008) examined blog usage by cancer patients. 113 cancer

patients and their companions were surveyed about their blogging activities.   Results of

the survey revealed that these individuals frequently read blogs; posting to blogs was

done far less often. Participants felt that blogging created a venue that allowed them to

express their feelings about their cancer, seek out strategies to manage their cancer,

problem-solve, and to share information with others.

The field of online diary or weblog research is still in the infancy stage (Cohen, et

al, 2006). Weblogs provide an inexpensive, readily available source of data for

researchers. The use of diaries in research has been proven to be effective in providing

important data for researchers. Weblogs are in essence diaries recorded in an electronic

format rather than pencil and paper. For this reason, the investigator felt that the study of

weblogs by bereaved families would also yield rich data.

Participants

The content for the weblog entries in the present study originated from the

CaringBridge website. CaringBridge is a non-profit organization web service which

provides families with a website to "keep loved ones informed during difficult times"

(CaringBridge, 1997-2009). Families are given information about CaringBridge by a member of the healthcare team. In the pediatric setting, this is usually a social worker or child life specialist. Families who choose to participate are instructed to go to the CaringBridge website to set up a personal account and to create a password. From that point, the information posted on the daily weblog is controlled by the owner of the CaringBridge account. Access to the CaringBridge weblog is limited to those who know the name of the family's weblog page. Others may view the weblog entry and sign a guestbook, but no one may post to the weblog pages without the appropriate password.

This study examined the weblogs of 10 families from the United States who had experienced the death of a child due to cancer. Although childhood cancers are rare, approximately 10,700 children between the ages of 0 and 14 were expected to be diagnosed with new onset of cancer in 2010 alone (American Cancer Society, 2010). It was also estimated that 1300 children would die from cancer in 2010, with about 1/3 of those deaths due to leukemia. Childhood mortality rates have declined, but cancer remains the second leading cause of death for children; accidents are number one. The diagnosis of cancer was chosen over other causes of death because it was most likely that these families, due to the nature of their child's disease and treatment processes, would have been participants in a CaringBridge website.

Five of the weblogs in the present study originated from the Midwest; three were from the East and two from the South. All of the weblog entries were written in the first year following the death of the child.   The authors of these weblog entries were primarily the mothers in the families, although there were a few entries by fathers.   The sources of

the data were the weblog entries written about children who had died from cancer, primarily leukemia. At the time of their deaths, the ages of these children ranged from 13 months to 16 years. There were five boys and five girls.

The families were a mix of single (1), married (8), and blended (1) parent homes. Eight of the 10 families had other children living in the home at the time of the child's death; the other two families experienced the birth of their second child during the year after the death of the first child.

Procedure

Inclusion and exclusion criteria. Selection of participant families used the following inclusion criteria:

1.   Family will have used a CaringBridge website for their weblogs

2.   CaringBridge site remains open/accessible since the death of the child

3.   Child's death from cancer occurred at least one year prior to the study.

4.   Weblog author is English speaking and is able to read and write in English

5.   A minimum of 3 weblog postings will have occurred since the child's death

6.   Weblog author is an immediate family member or guardian of the deceased child.

Exculsion criteria included the following:

1. Non-English speaking/writing

2. Use of other weblog platforms, such as MySpace or Facebook

3. Recent death of child [less than 1 year ago]

4. Death of child due to a diagnosis other than cancer.

These inclusion and exclusion criteria were important because they helped the

investigator to focus on the study question. This study looked at the lived experience of

families who lost a child to cancer at least 1 year ago. By setting the inclusion criterion

of 1 year post-death of the child, the weblog entries had already been written. The

minimum of three weblog postings provided at least 30 weblog entries to be analyzed.

However there were a total of 440 individual entries that were analyzed; this translated

into 15,000 lines of text. The interval of one year was chosen because most families

receive support from friends, other family members, and support groups during that first

year (Arnold & Gemma, 2008). The initial year was also a series of continued "firsts",

such as the first Christmas without the child, the first birthday without the child. These

"firsts" for the family were likely be described in the weblog entries.

Recruitment.   Recruitment of participants followed all approved University of

Minnesota IRB policies and procedures. Additional IRB approval was obtained through

Children's Hospitals and Clinics of Minnesota. A letter inviting families to participate

was sent to the lead chaplain at Children's Hosptials and Clinics of Minnesota's Family

bereavement program. This letter was shared with 44 potential families in a mailing sent

out by the bereavement program. Additionally, the letter was sent to the key contact for

regional chapters of Candlelighters, a support group for bereaved parents [See Appendix

A, Recruitment Letter]. The investigator did not attend any sponsored events for either

group to do face to face recruiting in order to protect the privacy of the families who

participate in the programs and to avoid causing families to feel obligated to participate in

the study. Families who were interested in participating contacted the investigator via e-mail or telephone. The investigator returned the contact, written consent was obtained from the weblog author(s) via a face to face meeting or through correspondence via the US Mail.

The investigator recognized that it was possible that additional participants would be recruited through word of mouth. Many families become close to each other during their child's illness; some CaringBridge weblog entries mention other children who are also hospitalized or going through similar treatments. Volunteers referred by other participant families went through the same recruitment process as those recruited through the primary method. If the family contacted the investigator by phone or by e-mail indicating an interest, a letter was sent to the family describing the study [Appendix B]. The family was asked to confirm their interest by an e-mail or telephone response. After that, consent was obtained from the weblog authors(s) via a face to face meeting or through US mail [see Appendix C, Consent form].

Despite exhaustive efforts to recruit families, over a 12 month period only five families responded to the invitation to participate. Of those five families, only 4 CaringBridge websites met the study criteria [one child had died < 6 months earlier]. An ammendment of the recruitment protocol was proposed and accepted by the University's IRB in which the investigator used old CaringBridge pages that were available on the internet but had not seen active posting by the weblog authors in more than a year. A simple web search using Google© was conducted using the key search words of "CaringBridge", "angel" and "cancer". CaringBridge was the platform for the weblogs

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of the study and cancer was chosen as the cause for the child's death. "Angel" was used

as this term is often seen as a descriptor for a deceased child (by parents) on the

homepage of the CaringBridge child's website. The resulting search yielded 374,000

matches in 0.10 seconds. Individual websites and lists of website links were included in

the results of the search.

The author proceeded to move through the searched results, examining each URL

as a possible source for content. Those webpages that were not created within

CaringBridge's platform were excluded. Some URLs, when selected, took the author

directly to CaringBridge pages. Other URLs were linked to pages that listed multiple

CaringBridge pages; these were not directly linked to CaringBridge but rather assembled

by individual web page owners. Many of these lists of multiple links were on pages that

were disease related (e.g., links to pages about children with Neuroblastoma). Others

were assembled by the parent of a child with cancer as a resource for other parents.

From this Google search, the remaining 6 families were selected. These webpages

were still accessible on the web, but had not seen active posting in at least 18 months; the

average length of time since the last posting was 27.6 months. In some cases, the

homepages themselves indicated that the family would no longer be posting messages.

In the end, a total of 10 Family Caring Bridge sites were chosen for this study.

The investigator believed that the number of 10 participant families was appropriate; it

exceeded the minimum standard of 6 for a phenomenological study as recommended by

Sandelowski (1995).

Data collection and Human Subjects Protection. In all cases, once the CaringBridge

site was found to meet criteria, a careful process of downloading the data was started.

The first step in the data collection process was to go to the CaringBridge site and copy

the weblog entries for the time period immediately following the child's death and

extending out to the one year anniversary of the death. These weblog entries were copied

verbatim from the family's CaringBridge weblog page and pasted into a Microsoft Word

document. Once all the weblog entries had been copied the investigator saved a

password-protected copy of this document on a CD. The CD was labeled with the family

number plus designation of "original" and placed in the corresponding locked file.

The investigator then returned to the Word document. Some CaringBridge

weblog entries appear in reverse chronological order; the most recent weblog entry shows

up first. In those instances, the investigator cut and pasted the individual weblog entries

so that they occurred in chronological order, beginning with the first weblog that was

written at the time of or shortly after the child's death. Once this had been completed for

all weblog entries, each line was then assigned a number sequentially in order to assist

with data analysis later on. A password-protected copy of the newly ordered and

numbered text was saved to a compact disc file (CD). The CD was labeled with the

family number plus the designation "numbered" and placed into the locked file.

The next step in the process was to remove all personal information about the

families, including individual names, locations, hospital names, etc. Weblog entries

were read through in their entirety and any identifiers [name, location, etc.] were

removed to ensure anonymity of the participants. This was done to ensure confidentiality

and anonymity for the participants. This file was again password protected and saved to CD with the family number and the designation "deidentified". The CD was placed into the locked file.

While the creation of documents and CD's may seem somewhat excessive, the investigator felt that this provided a solid record of how the data had been handled in preparation for analysis. If there had been a question along the way about the data, this intentional method of data storage ensured that the data could be retrieved at any point of the research process. Password protection served as an added measure of protecting the confidentiality rights of the participants.

Analysis Method. The text of each weblog entry was examined in two ways: first, as a chronological presentation of the family's year following the death of their child and second, as a linguistic representation of the family's experience during that year. Line by line analysis of the weblog entries was conducted and themes extrapolated using von Manen's lifeworld existential of *lived space, lived time, lived other*, and *lived body* (van Manen, 1997, pp 101-106).

The weblog entries studied spanned the course of one year, beginning with the child's death and ending at the one year anniversary of the child's death. At the time the data was taken, many of the weblogs had become inactive, with an average time lapse of 27.6 months since the last posting by the families. All of the weblog entries were kept in their original form (including spelling and grammatical errors) as they had been written

by the weblog authors. This text appears in the following data analysis without correction or editing.

The weblogs were reread several times for a sense of the whole, or essence. At this point another read-through was conducted and coding of texts was performed using van Manen's (1997) four lifeworld existential themes of *lived body, lived time, lived space and lived other*. Text from the weblogs was then added to each of the coded themes and further analysis of the data was conducted. Memoing occurred concurrently throughout the data collection and analysis processes. Memoing assisted the investigator to clarify thinking, revealed any pre-existing assumptions, and served as a record for ideas, thoughts, and feelings. Writing memos also provided a record of decisions made throughout the research process.

Ensuring Integrity, Quality, and Rigor. In order to ensure integrity, quality, and rigor, Lincoln and Guba's (1985) standards of trustworthiness were followed.

Credibility and Dependability. To ensure that the data was credible and dependable, the weblog entries were taken verbatim without correction of spelling or grammar. Care was taken to remove only identifiable data such as participant names and locations without compromising the narrative provided by the key informant(s). An original unedited copy was kept in a secure location for reference. Memoing was performed throughout the entire process.

Authenticity. To ensure that the data represented multiple realities and voices of the participants, weblog entries were taken verbatim without correction. The process of

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removing identifiable data was explicitly followed for all weblog entries. Care was taken

to ensure that participants met criteria for inclusion into the study; because the experience

of a child's death is unique to each family, there was representation of different realities.

Highlighted text was used to illustrate themes conveying the feeling of the family's

experience.

Confirmability.   The investigator remained objective throughout the process of data

collection and analysis in order to ensure that the data represented what the participants

provided.

Transferability.   Care was taken to present sufficient descriptive data of the process and

findings so that readers will be able to determine if it can be applied to other settings and

contexts.   The writing of memos served to enhance the recording of data.

Limitations and Strengths of design. One limitation that the author identified from the

onset of the study was that the weblog entries were written primarily by one member of

each family. The author recognized that the family's experience was represented through

the words of this one author and that the weblog writer's interpretation of the family's

experience may not have been a view shared by the rest of the family. It was possible

that content presented by a single member of the family was biased. The feelings,

statements, and beliefs expressed by the weblog author(s) may not have been congruent

with those of other family members.

Another limitation was that the content of the CaringBridge weblogs had already

been written; the only data available to be studied was what was there.

There are several strengths in the design of the present study. Diary research has proven to be an effective method of inquiry. The study looked at electronic diaries in the form of weblogs and, since weblogs take the form of self-narratives, the information expressed by the weblog authors fit well with the research method. Weblog content was a reflection of the web author's lived experience.

Unlike many diary studies, the weblog entries themselves had already been written; there were no instructions regarding the content or topics for the diary recordings. Because the information was already in print form, there was no need for transcription. One of the advantages to diary research is the enhanced ability to collect sensitive information that would be difficult to obtain through more traditional methods such as survey or interview (Hookaway, 2008). The CaringBridge weblog provided an opportunity for the weblog author to write about the family's experience.

Ethical considerations. The study received IRB approval through all affiliated agencies, including the University of Minnesota. At the time of this study, CaringBridge did not have a separate IRB review. Instead, they required a copy of the University's IRB approval letter along with written documentation from the investigator that was presented to their board of directors.

There were no known or anticipated physical risks associated with this study. Participants were recruited from a system that had built in support mechanisms. Participants considered to be at-risk (e.g., experiencing a difficult bereavement period) were not included in the potential pool of participants. For example, the family who

volunteered for the study but had only recently lost their child was not included in the study. Families who were recruited into the study were asked to complete a standard demographic information form; participation was voluntary.

As each line of text was examined, the author was mindful that the words expressed by the writers were those of real people who were dealing with a terrible loss. The author made a conscious decision to approach the text in a manner that would honor not only the words of these families, but also the children themselves.

Chapter Four: Findings

The specific aim of this study was to describe the experience for families from the time of the child's death due to cancer and continuing out for the next year after the death, as identified by the family key informant(s), the weblog writer(s). This chapter discusses the findings of the thematic analysis of the family web pages using von Manen's lifeworld existential of *lived space, lived time, lived other* and *lived body*.

In addition to examining the text from a chronological view of the family's experience, the weblog entries were also viewed for their linguistic content. As previously stated, line by line analysis of the weblog entries was conducted and themes extrapolated using von Manen's lifeworld existential of *lived space, lived time, lived other*, and *lived body* (van Manen, 1997, pp 101-106).   In the end, there were two facets to the themes of each life world existential; the first a question of "how do we…" and the second descriptors of how families attempted to answer that question.

Lived Space

Lived space plays an important part in the way that we experience our surroundings or the spatial dimensions of our world. How we feel can be impacted by the size, location, and our previous experiences within the space.   When looking at lived space from the context of the family, a physical space commonly shared by the members is the family home; this serves as a place to gather, to bond, and to coexist. Within that physical space there are shared areas as well as areas designated to the individuals.

Lived space from the context of the family is not only the physical structure, but also the structure of the family itself. Each member holds a certain space or place within the family. This place includes not only traditional roles (mother, child, sibling, etc.) but also unique attributes (the shy one, the funny one, the disciplinarian, etc) on the part of the members.

When a child dies, the surviving family members are faced with a difficult question: *how do we preserve a space in our family for a child who is no longer physically present?* While there is no correct or definitive answer, the families (in their weblogs) describe their attempts to make a place for the deceased child. This theme is described by the investigator as *Sacred Spaces, Special Places.* An additional theme is described as *Use of the Aesthetic to Tell the Family's Story.*

Sacred Spaces, Special Places

The family home. For these ten bereaved families, preserving a space in their family for the deceased child was accomplished in part by establishing a connection to the child via physical places that held special meaning for the family. The first of these is the family home.

From a phenomenological lens, home is viewed by individuals and families as a special, secure place that influences our very being. For the bereaved families, home became a place to retreat and a safe space in which to freely grieve the loss of the child.

One parent wrote:

I am hoping that starting work next week will help my sadness and this big void left in my house. I haven't been out of my house except for my trips to [store], [store] and the balloon store. My girls keep pushing me to get out with some friends, do something, but I'm not quite ready for that. I feel safe in my house and it's somehow comforting.

Home was the place where the family interacted with the child while the child was alive. After the child had died, home became a place where memories of the child remained. These memories of the child in the home helped amplify the connection to the child through their formerly shared space (home).

This weekend has been tough on your dad and me…I have come to the realization that work is easier because it is the one place that I was not with you so it doesn't seem so lonely, for you (sic) dad that time is harder because he knew where you and I were and would be in constant contact via phone to make sure things were going ok.

Within the family home, the child's room became a special place for the family to connect with the child. Families described leaving the rooms virtually intact since the child's passing; preserving this physical space represented preserving the child's space within the family.

I spent a lot of time in your room this weekend. Just sitting on your bed and looking out the window. You have always had the best room with that beautiful morning sun coming in. Don't worry I always straightened the bedspread when I

got up. Your room is where we spend lots of time. On the computer or even

watching TV. It is our place to be closer to you.

Cemeteries.   The author was surprised to discover another physical place that became

special and sacred to families: the cemetery where the child was buried. Nine of the ten

families chose burial for the deceased child; one family chose cremation. For the

families whose child was buried, the cemetery became a second space of meaning and

connection with their child. In some ways, the cemetery became an extension of the

family home.

> *[sibling] and I visit [child]'s burial site each day and [dad] visits two and three*
>
> *times a day. I haven't had much opportunity to go by myself but the two times I*
>
> *did, it was very comforting and cleansing. [dad] placed a picture of [child] in a*
>
> *glass mason jar(brilliant idea) which has helped to see his beautiful smile with*
>
> *each visit. There are so many thoughts and feeling that need to be sorted out for*
>
> *many of us.*

Families talked about going to the cemetery to "visit" the child almost as though the child

was physically present at another location. The postings about the visits to the cemetery

were casual in nature and alluded to a child "waiting" there to see them. All talked about

going to be with the child at this special location.

> *Last night, we celebrated July 4th holiday with our friends. Every year we go to*
>
> *[cemetery] and sit on the hillside to watch the fireworks. Last night was no*
>
> *different. [child] was already there waiting for us. His grave site is there and you*
>
> *can find it easily, just look for balloons and butterflies.*

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Families described decorating the child's gravesites in their weblogs as though they were any other room in the family home. Balloons, flowers, photographs, and toys were brought to the graveside and left there for the child. Sometimes the decorations related to holidays or events, while other times the decorations were of a more permanent nature.

> *…(we) decorated [child]'s grave today with an Autumn theme, we were out there for two hours crying, then laughing, then crying again.*

In addition to the cemetery as a sacred space, families chose other locations to serve as a memorial space for their child. Often these were specially constructed gardens, intentionally placed benches, or trees planted in special locations.

> *[dad] and I have been exercising our own creativity in working on the design for a suitable rainbow garden for [child],,, I'm looking forward to having something growing there to make my visits feel more purposeful. I hope I can manage to keep his small patch weeded and watered, a duty I think [child] will appreciate all the more because I hate gardening.*

Although the child was not physically present, families continued their relationship with their child in familiar spaces (home) and in new places (cemeteries, gardens, etc.). Families found these sacred spaces and special places served as a way to foster a sense of connectedness to the deceased child.

Use of the aesthetic to tell the family's story

In addition to the written entries depicting the family's experience, families chose to augment their weblog entries with aesthetic enhancements. The most common addition to the web entries was photographs.

For the older weblogs, photos were displayed on the home page of the website; newer pages had the photos included within the weblog entries themselves. The photographs served as part of the family's communication within the weblog entries, saying more for the family than their words alone. Some of the photos showed happier times before the child had died. Other photos that were posted depicted what was going on for the family at that time. For example, one family had recently decided upon and purchased a headstone for the child's cemetery plot and shared that with their readers. Photographs of events memorializing the child were also included during that first year following the child's death.

> *I also added a picture of the [racing] car (Thank you [name] for doing this special thing for my son) that went down the track first while the Scouts were holding their hands over their hearts in silence.*

Families who experienced the birth of another child in the months following the child's death would post pictures of both children.

> *I scanned in a couple of pictures of [child] when she was a baby. She looks a lot like [brother]. Much more so than [sister] does. Even [name] said that [brother] looks like [child]. I have some baby pictures of [child] that people can't tell if it is [brother] or [child]... I will post both of them, so you can see!*

Even though the child was no longer physically present, he or she was still a part of the family.

The photographs also served as an enhancement to the invitation to the readers to continue to check in with the family through the weblog pages.

We recently developed some new photos of [child] -- it's hard to accept that they will be the last ones. I'll be scanning them soon and plan to put them up on the page sometime this week. Thanks for checking in!

While narrative text and photographs were the standard fare for weblog entries, at times families would post things from the arts to convey what they were experiencing at that time. These included things like song lyrics, quotes from literature, and poems.

FROM DADDY…
"With Arms Wide Open," Creed

"Well I just heard the news today
It seems my life is going to change
I closed my eyes, begin to pray
Then tears of joy stream down my face

Well I don't know if I'm ready
To be the man I have to be
I'll take a breath, take her by my side
We stand in awe, we've created life

With arms wide open
Under the sunlight
Welcome to this place
I'll show you everything
With arms wide open
Now everything has changed
I'll show you love
I'll show you everything

With arms wide open"
[© Creed, 2000]

[child] -
This song has always reminded me of you. I'm not sure why other than it truly
expresses a fathers (sic) joy of the impending arrival of his "first born". I can't
begin to put into words the feelings I had the first time I laid eyes on you. You
were so perfect in every way.
I think about you every second, every minute, every hour of every day. Your
absence leaves a gapping (sic) hole in my life that is only filled by your memories.
I wish things could've been different, but, I understand that you have more
important things to do. I love you, my son!!!!!
Until we meet again...
Your "best friend"

In addition to the work of others, weblog entries also contained original works by family

members. One mother's poem reveals her pain of losing her child.

To My [Child]:

My heart still aches in sadness

and secret tears still flow

What it meant to lose you

No one will ever know.

Love, Your Mom, forever and ever

Lived time

Lived time refers to subjective time, not clock time or objective time. In other

words, lived time refers to how we perceive time, which can speed up or slow down

depending upon the experience we face.

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The chronology of the first year after the loss of their child.

The starting point for the weblog entries analyzed in this study was the temporal experience of the death of the child. All of the weblogs included an announcement of the child's death. Some were very detailed describing how the child was supported by the family members as the child died while others were simple messages telling of the child's passing.

> *Heaven's newest angel has rainbow socks and a devilish wit. [child], our cherished gift from God, passed away this afternoon, after fighting so long and so valiantly for the life he loved.*

The message marked not only the child's death, but the beginning of temporality of the family's life without the child being physically present.

> *After a few meetings with the doctors, chaplin (sic) and some recommended pictures, we walked away from [hospital] shortly after midnight. I never dreamed that I would leave [hospital] without [child].*
>
> *Please continue to pray for our immediate family and [child]'s grandparents. The shock of [child]'s death is an overwhelming struggle for each of us...in different ways and at different times. Please pray for God to help heal our broken hearts and increase our faith.*

Another parent wrote

> *There is so much that I want to say, but the words just aren't coming out this morning. It takes me too much effort to write them… My family is coping. It has*

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been really rough on all of us. The people who loved [child], and the people who

care for me are all hurting.

After the child had died, two of the authors chose to change their writing style to one that addressed deceased child directly. The other eight continued to write to their support network as they had prior to the child's passing. In all cases, the weblog authors believed that their work was being read and that their "audience" wanted to hear from them. When a period of time had lapsed without a posting by the weblog authors, the next entry often began with an apology for not writing and then an explanation of what was happening in the family's life.

In the beginning, the weblog entries were frequent, sometimes daily occurrences. As the first year without the child progressed, the weblog entries became less regular, but were still full of information about the family's journey through grief.

I miss having stories to tell about [child] and her latest antics or even updates on

medical stuff going on with her. Sometimes I think about coming here to write

about what the day is like -- are we handling things well or is it a hard day... but

that gets kind of boring... I remember always wanting other folks who had lost

their kids to update their site after the fact. So often they would update, but

mentioned too how they didn't always know what to write. So, I guess I'm not

alone in that. I guess I just have to find a "new normal" in my updates just like we

have to in everything else in life.

Families had their ups and downs in that first year. Weblog entries described family life with the surviving siblings in the household and for four families, the birth of new children into the family. Families described (in their weblog entries) times of remembering the deceased child with laughter…and with tears. An exceptionally difficult time for the family occurred somewhere between 3-6 months after the child had died. Families were aware of that milestone and they shared how hard it was for them during that time. One parent described going to the websites of other bereaved families to help validate what her own family was experiencing

> *I've read back on some other websites of folks who have lost their children as well and it seems we're not completely crazy. There does seem to often be a spike in grief around 6 months and then again around the one-year anniversary. I guess it helps to know we're average – just can't bring myself to use the word "normal")*

As the one-year anniversary of the child's death approached, families talked about the expectations of society to "move on" with their grief. The families recognized that their sadness and tears were something that they would live with, but wondered if they should take their grief underground.

> *Someone wrote in my guestbook that they were glad to see me moving on. I don't even know how to take that statement. I mean.... am I moving on? I don't know. I mention her every single chance I get. I am not uncomfortable when people bring her up, although sometimes it catches me off guard, and I start crying... which is OK. I don't mind crying. I think if I were gone and she was left, she would be*

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crying too. She loved me, as I loved her.

Does moving on mean you are "over it"? Probably not. But I equate it with being

over it, which I am not. I will NEVER be over it. It will never be OK that she died,

and that I am left.

At the end of the first year, the weblog authors provided a reflective summary of

the previous year. Some wrote tender messages to the deceased child, expressing how

much they were missed. Four of the ten families announced that they would be closing

or ending the weblog entries as they had "served their purpose".

This will more than likely be the last entry in this journal. I honestly didn't think I

would write again. But, I had to tell you how beautiful [child] is, I had to thank

you for all you have done. He was a gift to us all. We are better people because

of him. He was an angel on earth. We love you all. [Child] loves you all.

Thank-you and good bye.

The day to day experience of grief.

Prior to the child's death, the family's time was consumed with the day to day

caring for a child with a life limiting illness. When the child died, family weblog entries

described how time in the traditional sense seemed to stop for the family while the rest of

the world moved on.

[dad] and I started packing up [child]'s things last weekend. We finally felt ready

to stop tripping over bins and boxes in the foyer. It was an emotionally exhausting

weekend, but we got to relive a lot of memories…. In a way it feels good to be

moving forward again, our house had been frozen on [day child died].

For the families, moving on in the world became, as one parent put it, surreal. Things

that in the past were deemed important were now viewed in a different light.

> *All of the holiday preparations feel so strange – it's surreal to watch people*
>
> *hustle around as if their lives depended on creating the "perfect" Christmas. I*
>
> *was standing in the baking aisle at [grocery store] on Sunday evening,*
>
> *contemplating chocolate chips, when the woman standing next to me let out a*
>
> *shriek. "Oh, my God!" she lamented. "Don't tell me they're out of cardamom! I*
>
> *can't BELIEVE this is happening to me!" I wanted to take her by the shoulders*
>
> *and shake her, and tell her a little bit about what it's like to face a true nightmare.*

Faced with this alteration of time, families sought to answer the questions, *How do we go*

on living each day without child in our lives? and *How do we fill our time now?* The

family weblog entries described the attempt to move forward while grappling with this

altered concept of time. The themes that emerged were *Wanting time back, Firsts and*

lasts, Lost dreams, and What do we do with our time?

Wanting time back

In addition feeling as though time was altered after the death of the child, families

talked about wanting time back in order to relive special moments spent with their child.

When daylight savings time ended and we turned the clocks back on Sunday, I

couldn't help but think back to April, when we turned our clocks forward and lost

an hour. I want THAT hour back. I wish we could just pluck it out of time now –

an hour that knew no cancer, no chemo, and no sadness. What a wonderful thing

it would be if we could have just an hour a year to savor with those we have lost.

But, of course, that wouldn't feel like enough, either.

Things that seemed important to the family in retrospect became time that could have

been better spent with the child. Now that their child was gone, families reflected on

time lost, wishing they could go back and do over again those special times in order to

take full advantage of the precious moments they had with their child.

The only thing I feel guilty about is being talked into pre-planning his funeral

while he was still breathing. Alive. I missed out on two hours of his life when I left

this house to do that. I see many unexpected deaths at my place of work and their

funerals were not pre-planned and went well. If I could only hold him for those

two hours that I missed.....

Firsts and Lasts

 For the bereaved families, each day going forward is filled with "firsts" during

the year following the child's death. One parent wrote,

I woke up this morning in a really bad mood. Missing [child] so much. Every day

is another day longer than we have ever been apart, and the anxiety is building. I

just try to get through it. All the firsts... first warm day... first birthday, first easter

(sic)... it just sucks.

Things that were once looked forward to with anticipation were now to be faced for the

first time without the child. For example, one parent described the pain of the first return

of the school year without the child.

I want to tell the truth so here it is...every day is still horrid, I just try SO hard to

keep moving on. or keep moving. The first year and then more are the very

hardest-all the firsts.

I was flipping thru the paper this morning and can't look at the ads; it's the first

time I can remember that I won't be going school shopping. I hope I work on the

first day of school because I don't even want to see or hear the bus coming down

the street. I decided to buy a bunch of school supplies and donate them, I guess

that will make me feel a bit better, to do some good, to take my pain and do some

good.

In addition to the firsts, there was a lot of reflection on the "lasts" experienced by the

family and the impact those lasts had on future events.

We're not celebrating Holloween (sic), or Tgiving (sic), or xmas (sic) this year,

just too hard. And it's a mutual decision with me and the girls. Last Oct 31 was so

much fun, I remember it like yesterday. Ours will be the darkest house this

Friday.

Lost dreams

As human beings, our temporal makeup is of our past, our present, and our future. Our past includes our memories, which can at times influence our present experiences. Our future includes hopes and dreams, which also influence our present experience. Family weblog entries reflected on these lost dreams, with parents wondering what might have been.

> *Sometimes I think about how she would be had this last year been "normal". Would she be playing in her room... Would she be riding her bike to [name] and [name]'s houses? Would she get to visit [name] and [name]? Would I be yelling at her to clean up her room? To do her homework? We should be preparing for her to go to Jr. High. I shouldn't be sitting here at my computer crying because cancer stole her from me.*

The lost dreams not only included plans for the near future, but also sadness over the loss of extended future, including launching the child from the home to college, marriage, and the child's own family.

> *It is really hard to believe that she is never going to grow up. I sit here thinking how if there is something after this.. it won't be the same... how could it. If we are reunited again... I can't even fathom what it will be like... and in one regard... Who cares? She and I are missing out on her having a boyfriend, graduating from college, getting married, having children... it is so very different with a child than another relative.*

What do we do with our time?

Caring for a child with cancer was not easy for the families, but a burden they willingly took on and would have done forever if it meant keeping their child with them. When the child died, families wondered what they would do with the time that should have been devoted to caring for the child.

> *This morning, I realised (sic) that I don't have to worry about getting up 4 times during the night, I don't have to worry about dragging [sister] and [brother]... and figuring out how to fit everything in the car. I don't have to help [child] go potty. I miss it all so much. I miss all the crappy things I had to do. I would take the physically harder instead of this emotionally harder stuff.*

Following the child's death, the changes in the family's routine of caring for a child with cancer meant more time for the surviving members of family.

> *[dad] returns to work tomorrow (yet again, we owe many thanks to his wonderful boss and co-workers at [dad's workplace] for the generous time off), and I have been making lists of things to do to try to keep busy during the long, quiet days ahead. We have spent the past week or so just trying to make sense of life without [child]. I hadn't realized how much our days were structured around him, especially since his cancer diagnosis in [month]. Caring for him never felt like a burden, but suddenly I'm faced with a yawning chasm of free time. There are, of course, plenty of things to do around our long-neglected house, but none of those tasks are as satisfying as taking care of [child] was.*

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Lived Other

The lifeworld existential of lived other considers the meaningful relationships one has to selected others; these relationships provide a sense of purpose in our lives. Within the family boundary, the relationship between members influences the individual members as well as the family as a whole. For the ten families in this study, there was a strong assertion that although the child was no longer physically present, the child remained a part of the family.

> *This is what cancer does to a family. Instantly and forever they are changed. Even those that survive never get to go back to "normal." There's fear of relapse and those lovely things the docs call "late effects." For those of us whose loved ones don't survive, we have shadows. There are parts of us the sun can't reach anymore. Dark memories, guilt, sadness. We live our lives, laugh and love. But never all the way. Part of me will always be off to the side grieving for what is missing. [child] was more than my son, he was part of who I am, who I want to be.*

There was a commitment on the part of the family to keep the child's memory alive for all members of the family and to ensure that the child will always have a place.

> *I think it will be challenging, as time goes on, to keep [child]'s place in the family without becoming too mired in the past. It's so hard to think of years stretching before us, without [child]. It just doesn't seem possible that our family must*

continue without him, but I feel that the best way to keep [child]'s memory alive

and present for us is to remain strong as a family.

Weblog entries described the struggle families felt as they attempted to define themselves in their "new normal". They provided examples of their day to day efforts to conform to the logistical expectations of society (we are now a family with one less member) and their assertion that they will forever remain a family, even though the child is not longer present.

"Is that your first child?" I had been warned about this question... there is no easy

way to answer it. Answering it truthfully leads to other questions, the first of

which is usually either "is your older child a girl or boy?" or "how old is your

oldest?" I've been asked several times since [sister] was born, but it seems like I

was asked every time I went out this week. There's nothing wrong with the

question at all. I've asked it tons of times when I see a young family. It's just, for

us, the answer is hard right now. I've always answered honestly and then I just

pray that the questions don't keep coming. The question that really stopped me in

my tracks was, "How many children do you have?" [dad] was with me when we

were asked tha (sic) one, and after an awkward silence he answered for us. I

couldn't make my mouth move.

Families reflected on the relationships they had with each other before and after the child had died. Watching videos from the past showing daily family life provided confirmation

that their bonds were strong and that they were truly "a family". One weblog author

wrote

> *The videos were wonderful, though. Looking at them from my new perspective I*
>
> *can recognize things I didn't notice before. We touched [child] a lot, one of us*
>
> *was always running our hands through his hair or rubbing his back. We laughed*
>
> *a lot as a family and were constantly talking. [child] always had the full attention*
>
> *of one of us, if not both. He knew he was everything to us.*

Even as families recognized that their deceased child was still a part of their family, one

of the questions that became apparent through their weblog entries was *How do we*

continue to be connected to our child?   The themes that emerged include Metaphysical

signs, Hope for Reunion, and Keeping the Memory Alive.

Family's Continued Connectedness with the Child: Metaphysical Signs.

A strong theme within the weblog pages addressed a continued connectedness to

the deceased child through metaphysical "signs" or "messages" as interpreted by the

family members. While the child was no longer physically present within the family,

family members believed that they were given messages from the child. This belief was

so strong that they shared these experiences with those reading their weblog entries.

Messages through nature. Families wrote about the signs or messages that they received from the deceased child through nature. Some were ongoing signs from experiences of the past, for example the first dandelions of spring.

> *"Good news, Mommy!" [brother 1] called from the backyard when he got home from school on Friday. "[child] sent us more dandelions!" A few days before, I had spotted our first dandelions of the season, growing in a small clump next to the house, in the same spot where they had first surfaced last April. It was [child]'s daily chore last spring to pick every last dandelion from our yard and he took the responsibility very seriously -- every spare container in our house was filled with dandelion bouquets, presented lovingly and with great pride by a beaming [child]. So when I saw those first two dandelions braving the fickle [state] spring weather, I showed them to [brother 1] and we wondered if they might be [child]'s way of saying hello -- there was one for [brother 1] and one for [brother 2], followed the next day by blossoms for [dad] and for me.*

Another parent reflected on the deceased child's love of frogs.

> *I can't tell you how many tree frogs have jumped on or almost jumped on me this spring. [child] loved tree frogs. We have a frog stick on the front porch that she and her daddy used to use at this time of year to make the frogs on the porch jump. She loved to do that. There is actually a tree frog somewhere in our house right now. It jumped in last night when we got home. I tried to catch it, but only*

succeeded in chasing it into a plant. Then I couldn't find it. Trust me, [child] was

laughing her behind off at me trying to catch it.

Some believed that the messages from the child were in response to the family's current state, for instance when a family was struggling to pay the bills, the family expressed their belief that the deceased child provided a way for the family's income to be improved.

> *Did you see and hear about the hail storm in [home town] on Thursday? I think*
>
> *that was my boy. For two reasons. First of all, you may not know that [dad] used*
>
> *to work for a roofing and siding company bidding out jobs for storm damaged*
>
> *homes. He did very well. We've been nervous about money lately and have*
>
> *thought we may need to sell our house. I think [child] knew this and thought he*
>
> *would help out his daddy.*

For the families, signs from nature were interpreted that even though the child was no longer with them, the child was doing well. These signs included sightings of birds, butterflies, and other animals in the wild. For example, one mother wrote

> *As I was driving past the cemetery last evening on my way to work, something*
>
> *caught my eye...it was a beautiful bird flying alongside my truck, right by the*
>
> *driver's side window. I can't remember what kind it was, I'd have to look in*
>
> *[child]'s [book]. He would've identified it right away. The bird flew there for so*

long, I'm taking it as some sort of sign that it was sent from [child], that he was

telling me he was ok, flying free of pain.

Supernatural messages.   The other type of signs or messages that families perceived as

coming from the deceased child were unexplained events, almost supernatural.   These

would often come to the family during times of great sadness or stress. Some of the

messages came through photographs

> *The evening of his burial, I had taken a picture of the sunset and I was amazed by*
>
> *what I saw. If you look closely, you can actually see features of [child]'s face in*
>
> *the cloud formation. I thought I was loosing (sic) it but when I showed it to others,*
>
> *they saw it too.*

Sometimes the sign or message just appeared. One mother described the mysterious

appearance of a green gemstone during times of emotional stress.

> *[sister] brought me a heart shaped green [child] "gem". It was loose just the*
>
> *gem. Plastic, but I couldn't find anywhere it came from. She insisted that it had*
>
> *something to do with [child] …. I asked her where she got it, and she said it was in*
>
> *her book. (I have no idea what book or what she is talking about.) She kept saying*
>
> *that it means "that [child] loves me (her)." I put it aside on my desk and now it is*
>
> *gone, I can't find it anywhere.*
>
> *Two days ago, I was having a really rough day, I wasn't feeling well, I was in the*
>
> *midst of baking a cake, I was just entirely stressed out. I was sobbing at my*

computer. Just sobbing, writing to my friends in a group that I belong to, and feeling sorry for myself, and missing [child]. Finally, after a bit, I got up to clean up (the house was a disaster) and as I was cleaning, I once again, found a little green gemstone on the floor, in a place that there shouldn't have been one. I thought it was interesting. It really helped me focus on knowing that she still loves me.

Anyway. After I found the bracelet and I cleaned up the other things that were in the room. I was upset and I was yelling at [stepdad]... and I stepped on a green gemstone... AGAIN... in the middle of the dining room this time.   This is the third one I found, and I always find them when I am having a particularly hard day. [stepdad] thinks I am nuts.... but I think, it was meant this way. I mean, unless he is putting them there... it doesn't make sense, where are they coming from? I would *love* any logical answer.

Sometimes the signs or messages were interpreted by the family as an impish communication initiated by the deceased child. These signs might appear to one person in the family...

Last night you must have been messing with your dad and I a bit. First, when your dad was gone I swear I saw movement in the curio cabinet mirror. You know when you sit on the couch that you can see people in the kitchen, out of the corner of my eye I was sure I saw something move. I was the only one home so I don't know kiddo, you messing with me. Then oh about midnight your radio in your

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room goes off. It has not gone off before. I don't doubt that you could be behind

this.

…or to more than one member of the family.

I fell asleep on the couch in [child]'s favorite spot, [sister] fell asleep on me... and

[stepdad] was playing PS2. He went to bed very late I imagine. About 3:30AM...

our phone starts making noise. I look at it and it says that it was paging the other

handset. But the other handset was near me also. I had bought this phone so that

[child] could page me from another room. I would leave the one set with her, and

she could just press a button and when I answered tell me what she needed. I

turned it off, but it was still ringing when I took it into the bedroom, to tell

[stepdad] about it. He seemed freaked out too... LOL

Connection through dreams. In addition to describing metaphysical signs from nature

and from the supernatural, family members talked about the children visiting them in

their dreams. The connection with the child during dreams brought comfort.

Finally last night I dreamt of [child]. I had been thinking just before I fell asleep,

that the only signs of [child] were the ones that she used to reside here.   I woke

up from the dream, I actually woke up smiling. No details from it, just knowing

the dream was nice. When I was waking up, I remember hearing her voice in my

head saying things will be ok, and that I was doing great. I must have still been

dreaming because I swear I felt her touch my head. Now, that you probably think

I am crazy! I am not. I may have dreamt it all, but I don't care. I guess, if I can't

see [child] during my days, I can dream of her at night.

The dreams, although experienced by one person in the family, were discussed with other family members and also written about within the weblogs for others to review. The dreams did not just happen for the parents. Siblings also described the child's visiting them in dreams and the parent would share this with the weblog audience.

Well, I didn't have any dreams of [child] last night but we were driving to [city]

today and [brother 1] out of the blue told me that he was playing with [child] last

night. He told me that [child] came to the new house that we live in now and they

went into the basement to play with [brother 1]'s trains. I asked what he looked

like and he proceded (sic) to say that [child] had curly hair and he was wearing

Angel clothes. They were made of gold and only covered his butt and front and he

was wearing Nike tennis shoes. He was wearing his Angel wings but [child] took

them off when they were playing with his trains. [brother 1] said that [child]

brought an Angel outfit for him to wear too. He also said that [child] had two

tears in each eye because he was sad because he missed him. [child] told him that

he wished he could stay with him forever but he will come and play with him

again. [child] told [brother 1] that he has friends in Heaven and he named a few,

one being [name] and the other [name]. I continued to listen closely (remember I

am driving). He then said they played "store" and came upstairs and gave [dad]

and I a kiss then they got into [child]'s bed and went to sleep. [brother 1] then

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said...”hey mom, guess what?....[child] put his arm around me. I love [child] so

much mommy”. I asked [brother 1] what [child] thought of [brother 2] and

[brother 1] said [child] said he had chubby cheeks and his name ([brother 2]) is

more chubbier!! I didn't quite understand that last part but it made me happy the

entire day. I called [dad] immediately to share [brother 1]'s dream and it made

his day too.

Hope for a Reunion

In addition to the meaningful relationships between humans, lived other also refers to the relationship with God. While families did not address concepts of heaven, there were several weblog entries that talked about hope for a reunion with the deceased child someday in the afterlife.

I am in so much pain right now, and I know it will last until I join [child].

However, I feel blessed. I was so lucky to be his mother. He made me strong and

helped me get through his struggle. He helped me help him. People tell me I have

helped them be better parents. I tell them it was [child] and [sister]. My kids

motivate me to be a better mother. How can I not? They are gifts. They are

perfect. It makes me feel great that people feel they are better because they knew

[child]. I am so lucky to be his mother. I think he knew what his purpose was.

Families wrote about their belief that until the time of being reunited, the deceased child's role was to serve as an unseen guardian of the family, watching over them.

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I can't believe it has been 28 days since [child] left us behind. It seems like it was

just a few days ago. Most of the time that has past is a blur. The heartache will be

forever with us. It really helps to focus on him running and playing in heaven and

it is comforting knowing that he is watching over us each and every second.

Keeping the memory alive

A common theme found within the family weblog pages was a request to help the family to preserve their relationship with the deceased child. Families asked for help to remember the child and asserted the need that the child was not to be forgotten. For the families, this meant talking about the child,

When I bring her up, sometimes people just stare at me with a gapping (sic)

mouth. REMEMBER. SHE. WAS. JUST. HERE. If we don't speak of her, she will

die in everyones (sic) head but mine. I love her, and I need to hear her name, to

help me realise (sic) that she wasn't just in my dreams. To help me remember her

touch, and her sweet breath, and her pretty face.

It also included writing about the child,

First and foremost, I am committed to keeping [child]'s spirit alive in our family.

While she is physically removed from our family, I am hopeful that she will have a

lasting impression on each of us. This is where you can help. Oddly enough, my

memory is failing me. At times it is difficult for me to even look at a picture and

feel connected to [child]. Memories are slow to come to mind, and it would mean

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the world to me if you could share your favorite memories of [child]. It is my

intent to print out the entire website, the guestbook entries and YOUR

MEMORIES and bind them in a book for each of our children and for [child]'s

grandparents.

Families found hearing others talk about memories of the deceased child and reading

their stories about the deceased child helped their grief. It also gave the family a sense

that others wanted to continue to be connected to their deceased child.

Now, here's the favor that I'd like to ask of you – as we remember the anniversary

and celebrate [child]'s birthday on Friday, we would love to hear either your

memories of [child], OR the story of a loved one you have lost, and how you

maintain your feelings of connection with them. It's amazingly helpful to hear

other people's stories.

Lived Body

The last lifeworld existential involves ones corporal being. The experience of

grief brings many physical and psychological symptoms for family members. These

symptoms experienced by one or more members have an impact on the family (and the

family can have an impact on the individual's experience). In their descriptions of the

emotional pain and longing they were experiencing in their grief, the families were

searching for a way to heal. This need for healing was not just at the individual level, but

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for the family as a whole. The themes that emerged include *A Rollercoaster of Emotions, Longing for a Physical Connection*, and *A Hole in the Heart of the Family.*

Rollercoaster of emotions.

The emotional highs and lows experienced following the death of a child were frequently talked about by the weblog authors. The analogy of a roller coaster was used in several of the entries

Emotionally we are on a roller coaster. We have reasonably stable days and others where everything makes me cry for [child].

Another weblog author also talked about this rollercoaster of emotions.

I come here to update every few days, but I'm running out of things to say these days. I want to tell all of you that we're doing well and the pain is easing. But the truth is I feel like we're on a rollercoaster in the dark. I'm never sure what emotion is around the next corner. Sometimes I feel like I'm doing ok - like I'm starting to accept that [child] is gone and I'm starting to resume living. Other times I'm caught off guard by the sadness that still wakes me up in the middle of the night to find that there is no warm little boy cuddling his bunny between [dad] and I in our bed. Every few weeks a little bout of sadness that lasts 3-4 days hits me and I relive it all over again. Between those bouts I seem to cope ok.

The weblog entries shared how members of the family were dealing with the emotional impact of losing a son/daughter sister/brother.

[sister] is having a hard time with some of this. At times, she demands that [child] come back. I know how she feels, I feel that way at times also. [brother] now thinks that [child] is in the computer, because whenever I ask him where [child] is, that is where he points. Sometimes, I wonder how I am going to get past the next minute... other times, I am OK. I want to be happy, I try to be happy, I encourage others to be happy.... but I miss her so much. I almost feel guilty being happy.

In the first few months following the child's death, weblog entries described feelings of disbelief that the child had died. One parent talked about wanting to wake up from the nightmare

I still can't believe it... I mean of course, I do believe it, she isn't here... some mornings I wake up... I keep my eyes closed and hope I wake up and it was all a big nightmare. But, I know before I open my eyes that it wasn't a dream. It really happened. It was as much of a dream as my sweet [child] was. Honestly, I couldn't believe she was mine. Now that it is full circle... I wish she was still mine.

It gets worse.   Around 3-4 months after the child's death, weblog authors described grief that was more intense than it had been immediately following the child's death.

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It's been four months to the day of [Child]'s death and I'm still going through

pure hell. I hate this, nothing has ever hurt so bad in my entire life. I wish I would

have done things different, why can't I go back in time?

They acknowledged that the rough times they were experiencing were not unusual but
something to be expected.

I can also understand why people say that around 4 months is so hard... we are

almost to 3 now... but it really hits you, that they are NEVER coming back. My

time here with [child] is through. I will never stop loving her, I will never stop

being her mom. And she will never stop teaching me things.

The rollercoaster of emotions continued and the sadness was more intense.

I relapsed a bit last week for a few days, couldn't get the crying under

control...only when I went to work. I guess it's still part of the unknown ups and

downs of a rollercoaster ride of grief, pain, and loss. It's still so raw and tender

and hurts very bad. My buddy, my sidekick, my best friend, one-half of me, my

son.

Toward the end of the year, the weblog authors described the grief as still very much
present, but something that they were "getting used to" as a part of everyday life.

For me, grieving is something that I've kind of had to make peace with and accept

as part of daily life now. It's not always all-consuming, but it is always present.

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I've learned that I usually have a choice of dealing with the sadness when it

comes, or putting it off for a little while. I think it's ok to wade through it at times,

and put it off at other times so long as I don't do one way all the time.

The rollercoaster of emotions was replaced with a recognition that there will be ups and downs, sadness and joy, in everyday life.

How on earth have we made it a whole year without you? Without your sweet

voice, your catching giggle, your mischievous grin, and your sweet arms around

our neck. We miss you as much today was we did this same day last year, but we

have definitely learned a bit about grief and missing. I think, for me at least, the

biggest lesson has been in how to let grief be a part of the every day without

letting it govern my life. I've learned that I can miss you and still find happiness in

my days. Life will never, ever, ever be as sweet as it was before you left us, but I

know that wallowing would not make you proud. There are days that we wallow,

but there are days where we do a decent job of trying to live like you taught us...

full even when things are hard. Who knew how many lessons a [nickname] (I miss

hearing your daddy call you that) would teach us.

Longing for physical connection

In addition to describing the pain experienced when losing a child, many of the weblog entries talked about longing for the child to be back with the family.

In some ways the missing has changed to a longing for her. [dad] said something

yesterday that made me smile. He said that at least her being gone isn't going to

get any worse... she's already as gone as she can be. I think that's a good way to

look at it. He's usually good at finding a positive way of looking at things.

There was a longing to hold the child again...

Our family continues to miss [child] immensely and some days are more difficult

than others. Some days tears come from nowhere and the pain is ever so fresh in

our hearts. The longing to hold [child] again becomes a driven passion to live

each day to the fullest.

… a longing to touch the child again...

I miss talking with her, and kissing her sweet mouth, and holding her hand...

probably holding her hand specifically (sic) in the car is the hardest. She was an

avid hand holder... as am I.

…and a longing to hear the child's voice again.

This week, I missed [child]'s voice. I had not heard her speak since she was

intubated and I just needed to hear her voice. One day I woke up, and just had to

hear it. I popped in our most recent video tape and watched the whole thing. It

had stuff on it from [location] (getting tucked in by [character] -- What a hoot!!),

her birthday (the famous laugh when she opened a card from [name]), her sitting

on the counter helping me cook and singing Christmas songs, and Christmas

morning. What a blessing it was. I laughed, cried, smiled, and felt a whole lot

better after I watched it... good therapy...

Videotapes provided the opportunity to hear the child, although it wasn't quite the same.

I watched a video tonight. It was so good to hear her voice. It wasn't a video of

anything special, just kind of hanging out. That was better though, b/c you really

see her personality in the video. She tells us about chemo and cancer and her

birthday and she says, "I love you." Oh, how long it's been since we last heard

those words from her sweet lips. You see a bit of her feistiness and spunk too.

Plain and simple we miss her... plain and simple.

A Hole in the Heart of the family

The heart is often regarded as a symbol representing love and affection. The grieving families made several references to broken hearts, holes in hearts, aching hearts, etc. While heart is considered an individual concept, the use of heart by families in this case symbolized the essence of the family entity. The loss of the child created not only a physical absence of a family member, but also a void in the family as a whole.

Yesterday reminded me that we have lost the heart of our family. [dad] and I love

each other immensely and [child] was the physical manifestation of that love, he

was our joy all wrapped up in a little body.

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In short, the metaphysical boundary of the family is forever changed; the integrity of the

family has been disrupted.

Chapter Five: Discussion

The weblog entries presented the family's experience over the course of a year following the death of a child. Through their writing, the family weblog authors described the family's grief as it was occurring. The following is a summary review of the major themes:

Table 1		
Weblog Themes		Text Themes
	Family's question: *How do we....?*	Family descriptions of how they answer that question.
Lived Space	*How do we preserve a space in our family for the child who is no longer physically present?*	Sacred spaces/special places Use of the aesthetic to tell the family's story
Lived Time	*How do we go on living each day without child in our lives?* *How do we fill our time now?*	Wanting time back Firsts and lasts Lost dreams What do we do with our time
Lived Other	*How do we remain connected to the child?*	Metaphysical signs Hope for Heaven/reunion Keeping the memory alive
Lived Body	*How do we begin to heal?*	A Rollercoaster of Emotions Longing for Physical Connections A Hole in the Heart of the Family : Disruption of family integrity

Overall findings

The weblogs in this study started out as a source of information for the support network of the child and family during the time that the child was diagnosed and being treated for cancer. After the child died, the pages became a source about the process of grieving/bereavement that the family was experiencing.

Families, according to the weblog authors, were very candid about their day to day experiences with adjusting to a world without the deceased child. (It is important to note that the weblog authors themselves were grieving as individuals and as part of a grieving family.) That they were able to write with such clarity about the family's grief/bereavement experience is truly commendable.

In this study, family members experienced strong emotional feelings of loss and longing for the deceased child. Although the child was no longer a part of the family in the physical sense, the feeling of connectedness experienced by the families occurred in special spaces/places (lived space); within the family home or in places like the cemetery where the child had been buried. Time also played a strong part in helping the family as they grieved; notably reflection of memories/time past, realigning time in the present, and acknowledging the loss of future dreams (lived time). Connections to the deceased child often were expressed as metaphysical signs associated with the deceased child and holding onto hope that the family will be reunited together.

Links with existing research/Theoretical Considerations

This study clearly links with and adds to the loss concept elaborated by Bowlby while adding rich contextual information about <u>how</u> families experienced the stages of grief and what strategies they used in their grief work. The attachment to the deceased child is evident in the weblogs of all of the families and their descriptions of their grief are full of detail and emotion. The grief experienced by the families was shared, but not synchronous; this was evidenced in the descriptive entries by the weblog authors.

If the families did experience anticipatory mourning, there was no mention of that in their weblog pages. The families made reference to watching their child's condition decline and described in great detail the child's death, but none of the entries addressed or described situations where the family was grieving the child's impending death. This was somewhat of a surprise to the investigator as anticipatory grieving has been identified as helpful to families after a loved one has died (Ashton & Ashton, 2000; Fulton & Fulton, 1979; Rando, 2000).

This study clearly exemplifies that the integrity of the family was disrupted and that the psychological health of the family was altered (Tomlinson, et al., 2011). The metaphysical boundary of the family has changed as a result of the permanent absence of a beloved family member, the child. In their grief, these families showed resiliency as evidenced by the creative methods they employed to maintain a sense of connectedness to the deceased child in order to restore the integrity of the family system.

These weblogs suggest that talking about their deceased child helped these families in their grieving; findings that support Braun and Berg's (1994) study. Without

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exception, each CaringBridge page studied began with the description about the child's death. In the year that followed, families shared memories about the child and described their emotional journey as they navigated in this new world without the child physically present. The weblog entries were written for an audience that was unseen, yet the families felt a freedom to say what they wanted.

At the end of the first year, the grief that the families experienced was still very real but it had changed somewhat. In the time immediately after the child's death families experienced grief and shock that the child had died and their weblogs described that shock. A year later, the content of the family weblogs contained messages describing that their grief was present, but that they were adjusting to a world without their child in it. This supports the belief that grief never goes away, but changes (Arnold & Gemma, 2008; McClowery, et al., 1987).

Limitations and Strengths of the present study

There are three limitations in the study recognized by the investigator. First, the weblog entries represent a homogenous group in that they are all written about the experiences of families of children who died of cancer. While this is a strength for this particular study, this homogeneity is also a potential limitation. The findings of this study are not generalizable to the greater population of families who experienced the death of children from other causes, such as accident, homicide, or suicide. In this case it is unknown what role preparation for death of a child plays in family grief response.

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Another possible limitation of the study is the selection of the weblog pages for the study. Although 4 of the families were recruited, little is known about those families beyond what can be inferred from the weblog pages themselves. Even less is known about the remaining 6 families whose webpages were selected from internet searching. It is also not known why some families would choose to participate and others would not.

Another possible limitation is in the claims made that this is a family study. There was, for the most part, a consistent weblog author for each family (typically the mother); this continuity is yet another strength to the present study. The view of the family is seen through the lens of this weblog author and reported consistently over time. It must be pointed out that the information presented by the weblog author was their interpretation of what was happening in the family. It is possible that other family members may have held a differing opinion of the weblog author's observations. Further, because there was no opportunity to validate or clarify with the weblog author, the data had to be interpreted as is.

There were several strengths in the present study. Because grieving is a prolonged process for families, only longitudinal studies can capture that.. One of the strengths of this study the length of time that the data itself represents (one year). Other studies of family bereavement which represent a post facto, retrospective reflection of what was occurring at one particular point in time are also limited. In the present study, the family informants (weblog authors) composed frequent entries over the course of the first year, providing a fresh view of what is occurring for the family *at that moment in*

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time. Further, the weblog entries were unscripted, that is, the weblog authors were not limited or required to record certain events, emotions, or perceptions.

Another strength of this study is the sheer volume of entries that were available to be reviewed. These 433 entries provided data that was rich and deep with insight into the family experience providing context to the grief process not reported in most of the grief/ bereavement literature. Some may argue that in order to manage the data, the volume could have been limited to a pre-established number of entries. However, having a year's representation of the family experience truly exemplifies their day to day challenges and successes as they begin to adjust to a family without the child being physically present.

Ethical considerations

CaringBridge pages are, by definition of the CaringBridge organization, the property of the weblog authors. When the CaringBridge pages are initiated by the weblog authors, it is typically in response to a crisis; families would not have a CaringBridge page for normal day to day communication of family events. Access to the family weblog requires some knowledge about how to find it within the CaringBridge site. For some, this access is the child's name; for others, there is additional security required such as a password or registering upon entry into the webpage.

While CaringBridge weblogs are part of the internet and generally accessible to anyone who knows how to locate them, it must be stated that caution should be employed if using the weblogs for research. The investigator was keenly aware throughout the present study of the need to respect the privacy of these families. Care must be taken to

ensure that the data (and the families themselves) are protected and that the research

process does not become voyeuristic. The CaringBridge pages contained information

about the child and family starting at the time of the child's diagnosis; the investigator

did not view any of those entries. Additionally, in their weblog entries, some families

made references to messages posted by their support network in the Guest Book section

of their web pages; the investigator made a conscious decision to view only the webpages

that were a part of the study.

Future research

When the families in this study began using their CaringBridge pages their child had

been diagnosed with and was being treated for cancer. However, the weblog authors also

described writing updates every day, sometimes more than once a day while their child

was living. Those entries were not included in the present study. If the richness of the

data in the year following the child's death is any indication, studying the weblogs in the

months preceding the child's death may yield valuable information about the concept of

anticipatory grieving.

The entries after the child had died came less regularly (as stated by the weblog

authors themselves), often with an apology for not having written in a timely manner. As

the first year of grieving came to a close, the CaringBridge pages became less useful to

the family; possibly evidence that the CaringBridge pages were likely no longer needed.

In fact, several of the weblog authors wrote at the end of the year that they were going to

be decreasing the frequency of the weblogs or closing down the pages altogether. Was

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the crisis for the family now in the past? Was the disruption of the family's

boundary/integrity that was experienced with the death of the child now resolved? An

area for future study includes the analysis of the CaringBridge pages in the second year

after the child had died.

The CaringBridge authors were very open about the experiences of their family in the

year after the child had died. But what about the families that do not use CaringBridge?

Do they use other social media websites? Do they opt not to use any social media

websites to blog? An interesting question to be explored is who uses CaringBridge, who

does not, and why?

It can be speculated that the act of writing weblog entries in the year following the

child's death is a therapeutic intervention for the authors. However, this study did not

determine that, leaving a compelling area for future study.

Implications for nursing and other members of the health care team

Nurses are not just providers of physical and emotional care. One of the other

responsibilities of the profession includes education. In general, nurses do a good job of

instructing individuals and families about what to expect as a member of the family is

dying (Miles, 1984; Rini & Loriz, 2007). Unfortunately, this is often where the education

stops. Nurses should also provide anticipatory guidance for families for the grieving that

happens after their loved one has died.

The data in this study showed how families struggle as they adjust to a world

without the child physically present.   They seek ways to remain connected to their

deceased child, create and preserve special places that provide a source of connection

with the child within the home, at the cemetery, and in gardens, find comfort in symbols

of nature and other metaphysical signs, and hold onto memories through videos,

photographs, and other aesthetic representations of their relationship with their deceased

child. Nurses should acknowledge that the grief families experience (while unique) is

something that other families have gone through. For example, in helping a family who

is grieving, a nurse may offer that some families have found that preserving a special

place for the child's belongings in their home creates a sense of connectedness to that

child.

Another implication for nursing involves family support during the bereavement

period following the child's death. Families described in their weblogs that when the

child was dying, they (the family) experienced an outpouring of support from friends and

also from the Health Care team.   According to them, shortly after the child's death, this

support seemed to have stopped, creating grief for the loss of their support system [see

Appendix D for supporting evidence].

Health professionals are obligated to look at the family's support network,

providing guidance to the family when external support is needed. Again, as nurses (and

other members of the health care team) work with families, the message about being

intentional or direct when asking for help from the support network should be

emphasized. There is help to be had from the family's circle of support. All they have to

do is ask.

An often overlooked but important source of support for the family is the

healthcare team itself. Nurses, physicians, and other members of the health care team in

the hospital and in the clinics, by the very nature of their relationship with the family, become an extension of the family's network. This was identified in the weblogs.

Some children died in the hospital, while others died at home under hospice care. Regardless of location, families talked about the closeness they felt to the healthcare team. For these families, their relationship with the healthcare team changed when their child died. At some point during the first year, families made trips back in to the hospital or clinic to reconnect with the nurses and physicians. Unfortunately, for at least one of the families, the experience of support from the health care team was less than satisfying.

In short, nurses (and the health care team) should continue to support the family in their grief. This may be as simple as a phone call to check in with the family, or a visit with the family perhaps during a time that may be particularly difficult (e.g., the first day of school).

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Appendix A: Recruitment Documentation

Children's Hospitals and Clinics + Candlelighters

Dear CaringBridge User,

I am a doctoral student in the School of Nursing at the University of Minnesota. My thesis work involves a study of families' experiences after a child has died, as seen through their CaringBridge journal or weblog entries. Specifically, the purpose of my study is to look at the experiences described by families in their CaringBridge weblog entries during the months that follow after their child has died. This study only looks at the entries that you made in the journal portion of your CaringBridge website. It does not include the messages left by others to your guestbook.

Your risks for participating in this study are minimal. This study involves weblog entries that have already been written. You will be asked to sign a consent form for this study. You will also be asked to complete a brief form asking you some general questions about demographic information; you can decline to answer any or all of these questions. And finally, you will be asked to provide the name of your CaringBridge website page.

There are no benefits of participation for you and there is no compensation for this study. I am looking for active CaringBridge websites for children who died from cancer at least one year ago. Before doing anything with the journal entries, I will remove all identifying information such as names, cities, hospitals, etc. In any report or presentation that is published, I will not include any information that makes it possible to identify you or your family.

If you are interested in participating in this study or learning more about this study, please contact me by phone at 952-913-8697 or by e-mail sher0207@umn.edu.

Thank you for considering my request.

Sincerely,

Suzan Sherman

Appendix B: Recruitment Documentation

Recruitment Letter for those who are referred to investigator from outside sources.

Dear _____,

Thank you for expressing an interest in this study. I know that you were referred to me by someone who is familiar with your Caringbridge website. Let me share a little more about the study.

I am a doctoral student in the School of Nursing at the University of Minnesota. My thesis work involves a study of families' experiences after a child has died, as seen through their CaringBridge journal or weblog entries. Specifically, the purpose of my study is to look at the experiences described by families in their CaringBridge weblog entries during the months that follow after their child has died. This study only looks at the entries that you made in the journal portion of your CaringBridge website. It does not include the messages left by others to your guestbook.

Your risks for participating in this study are minimal. This study involves weblog entries that have already been written. You will be asked to sign a consent form for this study. You will also be asked to complete a brief form asking you some general questions about demographic information; you can decline to answer any or all of these questions. And finally, you will be asked to provide the name of your CaringBridge website page.

There are no benefits of participation for you and there is no compensation for this study. I am looking for active CaringBridge websites for children who died from cancer at least one year ago. Before doing anything with the journal entries, I will remove all identifying information such as names, cities, hospitals, etc. In any report or presentation that is published, I will not include any information that makes it possible to identify you or your family.

If you are interested in participating in this study or learning more about this study, please contact me by phone at 952-913-8697 or by e-mail sher0207@umn.edu.

Thank you for considering my request.

Sincerely,

Suzan Sherman

Appendix C: Consent form

Consent Form
Family weblog entries

You are invited to be in a research study of the weblog [journal] entries of families that were written after the death of their child. You were selected as a possible participant because of your use of Caring Bridge as a way to tell your family's story. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Suzan Sherman, a doctoral candidate in the School of Nursing at the University of Minnesota.

Background Information
The purpose of this study is to look at the experiences described by families in their CaringBridge weblog entries during the months that follow after their child has died. This study only looks at the entries that you made in the journal portion of your CaringBridge website. It does not include the messages left by others to your guestbook.

Procedures:
If you agree to be in this study, we would ask you to do the following things:
Provide the website name for your Caring Bridge site
Complete a brief information sheet [all questions are optional]

Risks and Benefits of being in the Study
Your risks for participating in this study are minimal. This study involves weblog entries that have already been written.

There are no benefits of participation for you.

Compensation:
There is no compensation for this study. However, if you would like a copy of your original weblog entries burned to a CD, one can be mailed to you.

Confidentiality:
The records of this study will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify a subject. Research records will be stored securely and only researchers will have access to the records.

Once your entries from the journal section of CaringBridge have been downloaded to a disk, all identifying information about your family [names, locations such as cities, place

of work, hospital or clinic, etc] will be removed. A copy will then be saved with a special password, labeled with a study number, and placed in a locked file cabinet.

Voluntary Nature of the Study:
Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota, Children's Hospitals and Clinics, Compassionate Friends, or CaringBridge. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

Contacts and Questions:
The researcher conducting this study is: Suzan Sherman. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact me at 952-913-8697 or through my e-mail sher0207@umn.edu. You may also contact my advisor, Dr. Cynthia Peden-McAlpine at the University of Minnesota by phone 612-625-0449.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), **you are encouraged** to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.

You will be given a copy of this information to keep for your records.

Statement of Consent:

I have read the above information. I have asked questions and have received answers. I consent to participate in the study.

Signature:_____   Date: _____

Signature of parent or guardian:_____   Date: _____
(If minors are involved)

Signature of Investigator:_____   Date: _____

Appendix D: Supporting Documentation

Supporting documentation for perceived loss of support from members of the Health

Care Team.

> *People came when we found out that [child] was going to die. But after she died,*
>
> *they left. It is HARDER to live now, than it was to live watching her die.*

In their weblog entries, families described this loss of support and subtly asked for the

friends to return.

> *People keep saying that they figured I am bombarded with people coming over*
>
> *and they don't want to bother me. Well, truthfully, I think everything thinks that,*
>
> *and no one comes. So please, if you feel like bothering me... bother away. I could*
>
> *use the company.*

When the family made specific requests from the friends, these were immediately met.

The families soon recognized that they needed to be more direct in their asking.

> *I finally got enough guts to pick up the phone and ask my friends for help, and I*
>
> *seriously needed help even if it was having someone with me. And the bonus of my*
>
> *bathroom cleaned and carpets vacuumed was great. I have SUCH great friends,*
>
> *[name] and [name] came over yesterday after work and [name] is coming over*
>
> *Saturday after I get off work. I find it necessary for me not to be alone for long*
>
> *periods at a time. Don't be afraid to call me, as some people have said they are. I*

need people around me to get me up and moving and to talk to. The talks, laughs, and cries helped me in a big way, thank you ever so much. [family dog] is a pretty good listener, but he doesn't give me too many answers.

As I should have known, the church was packed, with people standing in the back, and it was heartening to see so many of the doctors, nurses, teachers, therapists, and others who took care of [child] throughout his life, among our friends and families, our distant relatives, our relatives' friends, our friends' relatives... truly, [child] had a LOT of friends.

We miss our nurses and docs as well... you really get attached to those folks who take such amazing care of you and they really feel like family. Hug each other for us if you read this and know we think of you often.

The bond you form with your doctors when your child is critically ill is so close, at least it was for me. They stand with you side by side as you fight tooth and nail to give your child every day possible and to make each day as good as possible. We will always, always be thankful for Dr. C, Dr. C, Dr. H, and all of our amazing nurses for all that they did for us. Each one holds such a special place in our hearts. It was good to catch up and just chat this weekend and I'm so thankful that I had the chance to do so.

[Biological dad] came over the other day... he really needs some counceling (sic).

He wants it. He tried calling the hospice people but, the guy only calls him once

in a while. Never when he says he will... and [biological dad] is getting

frustrated. They haven't called me either... sometimes I think I am missing out on

something by their not calling, but perhaps not. I am not ready, or do I think it

would help so much to talk to someone anyway. I talk to a lot of people online,

other grieving parents by phone, and other brain tumor parents by phone too. If I

need someone, I have people standing by in 5 countries waiting to listen. I just

wish someone would help [biological dad] out. He feels so lost.