

GRIEF AND CHARITY: EXPLORING THE RELATIONSHIP BETWEEN GRIEVING
THE DEATH OF A CHILD AND RESULTING CHARITABLE INVOLVEMENT

By Sarah E. Hanson

A dissertation to fulfill the requirements for a

DOCTOR OF PSYCHOLOGY IN COUNSELING PSYCHOLOGY

at

NORTHWEST UNIVERSITY

2014

Signatures omitted for security reasons.

Approval Signatures:

Jacqueline N. Gustafson, Ed.D. Dissertation Chair	Date:
---	-------

Sarah B. Drivdahl, Ph.D. Dissertation Committee Member	Date:
--	-------

Rachel Binns Terrill, Ph.D. Dissertation Committee Member	Date:
---	-------

Larry W. Bailey, Ph.D. Program Director	Date:
---	-------

Matt Nelson, Ph.D. Dean of College of Social and Behavioral Sciences	Date:
--	-------

Abstract

Experiencing the death of a child is a traumatic and horrifying experience for any parent. The topic of grief is well researched; however, there seems to be a gap in the literature as it pertains to ways parents respond to a child's death. There are many foundations and charities in existence today that have been established in honor of a deceased child. This phenomenon of establishing a foundation seems to be increasing as a common way for parents to respond to their child's death. How does the establishment of these charities and foundations affect the grieving process for the parents of the deceased child? This study sought to explore one woman's experience with establishing a foundation in response to her son's death. The method used for this study was qualitative with interpretative phenomenological analysis (IPA) with a single participant. The researcher chose to use a single participant because the experience was exemplary of what my research was seeking to explore. It was found that establishing a foundation to carry on the legacy of a deceased child did give the participant a reason to get up each day and proceed with life; however, it also seemed to lock her into repeatedly retelling and reliving the traumatic experience. It was also found that establishing the foundation did not give meaning to her son's death, but it did offer meaning to her life.

Keywords: grief, charity, child, death, foundation, meaning, pediatric cancer

Table of Contents

Abstract.....	2
Table of Contents.....	3
Acknowledgements.....	6
Dedication.....	8
Chapter 1.....	10
Introduction.....	10
Literature Review.....	11
Death and the grief process.....	11
Meaning making in grief.....	13
Positive aspects of grief.....	15
Parental grief and pediatric cancer.....	18
Significance of the Study.....	22
Research Questions.....	23
Limitations and Assumptions.....	23
Limitations.....	24
Assumptions.....	24
Summary.....	25
Chapter 2.....	26
Philosophical Worldview.....	26
Purpose Overview.....	26
Research Questions.....	27
Definition of Key Terms.....	27

GRIEF & CHARITY	4
Population and Sample	28
Methodology	29
Data collection.	30
In-depth interviews.	30
Focus group.....	31
Documents.	32
Observations.	32
Data analysis process and procedures.....	33
Credibility, Validity, and Reliability	35
Protection of human subjects.....	37
Summary	38
Chapter 3	39
Question 1	39
Carin's grief experience.....	41
Starting Ben Towne Foundation.	44
Current state of grief.	47
Question 2	50
No meaning in death.	51
Meaning to life.....	53
Response to suffering.....	54
Question 3	56
Work stress.....	57
Grief.....	58

GRIEF & CHARITY	5
Anger.....	58
Legacy.....	59
Vulnerability.....	60
Tension.....	61
Question 4	63
Summary	68
Chapter 4.....	70
Meaning	70
Closure	74
Future Direction and Implications	77
Conclusion	78
References.....	80
Appendix A.....	86
Appendix B.....	89
Appendix C	91
Appendix D.....	93

Acknowledgements

Many people have supported me through my graduate studies. The faculty and staff at Northwest University have enabled me to excel and to succeed at a high level. My dissertation chair, Dr. Jacqueline Gustafson, has dedicated her time and expertise toward helping me become the person, professional, and researcher I am today. Your determination, commitment to excellence, and global outlook inspire me. Thank you for speaking some tough words of truth to me this past year, “pain is real.” I will never forget. Thank you to Dr. Sarah Drivdahl and Dr. Rachel Terrill for being on my committee, offering feedback, and investing in my work. Carin Towne, thank you for allowing me to focus my dissertation on your life. Your courage and vulnerability in sharing your story will stay with me always, and I am honored that you would let me into your pain and sorrow. Thank you, also, to the four focus group women who shared their personal and tragic stories with me. I so appreciated your time, understanding, wisdom, and even humor: I did not expect to laugh as much as I did.

Thank you to Bob Novak, assistant librarian at Seattle University. Your kindness in helping me find research literature was incredibly helpful and significant. Sarah Nystrom, thank you for all you did to help me with this process. From editing, to proofreading, to processing through the findings with me, you helped me to move forward and ultimately finish. Thank you to Julia Young whose talent and skill helped me beautifully express the story of my research.

Thank you to my parents, Jim and Joy Zorn, who taught me how to persevere even when things get tough. Your willingness to help with so many areas of my life so I could continue to accomplish my goals was an incredible gift that I will never be able to

pay back. Rachael Mitchell, thank you for helping me make lists, feed my family, take care of Hope, process my findings, and cheering me on throughout this whole process. I owe you many hours of babysitting and dinners. Dani Zorn, thank you for helping with Hope, coming to class with me, and making yourself available when I needed you. You helped keep me sane throughout this process. Thank you for being my faithful friend. Isaac Zorn, we are the psychology “experts” in the family. Thanks for asking about my paper’s progress and making me feel really cool when you marveled at its length. Darin Hanson, your support and love kept me going. I could not have made it without you and your constant and firm commitment to my studies. I so value and appreciate your patience and sacrifice, and I know you are just as excited as I am to have finished. Here’s to many more years of marriage post-dissertation. To my sweet Hope, you came into the world while I was working on this dissertation. There were many times I just had to hold you tightly as I realized the fragility of life. I am thankful to God that He allowed me to be your Mom, and even more grateful that He loves you more than I ever could. I am continually humbled by God’s grace and love towards me.

Dedication

In dedication to Benjamin Ward Towne, a courageous and determined young boy. You are loved and incredibly missed.

I measure every Grief I meet
With narrow, probing, eyes –
I wonder if It weighs like Mine –
Or has an Easier size.

I wonder if They bore it long –
Or did it just begin –
I could not tell the Date of Mine –
It feels so old a pain –

I wonder if it hurts to live –
And if They have to try –
And whether – could They choose between –
It would not be – to die –

I note that Some – gone patient long –
At length, renew their smile –
An imitation of a Light
That has so little Oil –

I wonder if when Years have piled –
Some Thousands – on the Harm –
That hurt them early – such a lapse
Could give them any Balm –

Or would they go on aching still
Through Centuries of Nerve –
Enlightened to a larger Pain –
In Contrast with the Love –

The Grieved – are many – I am told –
There is the various Cause –
Death – is but one – and comes but once –
And only nails the eyes –

There's Grief of Want – and grief of Cold –
A sort they call “Despair” –
There's Banishment from native Eyes –
In sight of Native Air –

And though I may not guess the kind –
Correctly – yet to me
A piercing Comfort it affords
In passing Calvary –

To note the fashions – of the Cross –
And how they're mostly worn –
Still fascinated to presume
That Some – are like my own –

Emily Dickson, *I Measure Every Grief I Meet* (561)

Chapter 1

The purpose of Chapter One is to provide the reader with an understanding of the purpose of this study, to give an overview of the literature reviewed during the course of this study, and to introduce the research questions which guided the study.

Introduction

Jessica, Samantha, Rehma, Zachary, Alexandra, Elena, Pablo, Chelsea, Katie and Ben. Each of these names has something in common. They are all children who have tragically died, and because of their death a charity or foundation has been established.¹ These charities are each making significant differences in the lives of children and families across the nation. But what are the personal stories behind each one? Have their families found peace? Does the fact that the charity helps others somehow justify the injustice of losing a child? From the outside, it often appears that these families have found solace in doing something in memory of the child that died. But what are the true experiences?

One recent example of this is the Paul Lee Foundation. Paul Lee was a freshman at Seattle Pacific University who was fatally shot on June 5, 2014 by a gunman on campus. On June 12, 2014, an article was posted which stated that the Lee family had announced they were establishing a foundation in honor of Paul, and it would focus on helping people who struggle with mental illness (Koin 6 News staff, 2014). Upon hearing about this, I wondered whether the establishment of this foundation gave the parents a

¹ Jessica June Child Cancer Foundation, The Joyful Child Foundation (Samantha), The Rehma Fund for Children, Ball Parks 4 Him (Zachary), Alex's Lemonade Stand, The Cure Starts Now Foundation (Elena), The Pablove Foundation, Chelsea Rae Elbert Trust, Katie's Comforters Guild, Ben Towne Pediatric Cancer Research Foundation.

way to make sense out of the loss of their son. Is this foundation a way to distract from the pain? Is it a way to help them move forward? Was it even something they really wanted to do or was it in response to the anger and pain they felt, and this was a socially acceptable way to express that pain and anger? This example was a reminder of what originally drew me to this topic.

In this study, the goal was to learn about the lived experience of a woman who lost her child to pediatric cancer and has started a research foundation to find a cure. The intent was to discern whether or not creating a foundation in honor of a deceased child is helpful and healing to the parents in the grieving process. Interpretative Phenomenological Analysis (IPA) was the methodological approach to the study. According to Shaw (2010), the central goal of IPA is to “understand what personal and social experiences mean to those people who experience them” (p. 178). This case was chosen because Carin, and the Ben Towne Foundation, is a prominent regional example of what I was interested in understanding and researching.

This chapter presents some foundational and current literature as it applies to the researched topic. The significance of the study, definition of terms, and the specific research questions follow the literature review.

Literature Review

Death and the grief process. There are many different models and theories related to the process of grief (Holland & Neimeyer, 2010; Gillies & Neimeyer, 2006; Bowlby, 1980; Kubler-Ross, 1969). To think often of death may seem morbid and pessimistic. Never thinking of death might seem like denial or avoidance. Kubler-Ross

(1969) believed that society should habitually think about death and dying, at least occasionally. Kubler-Ross (1983) researched the experience of losing a child to terminal illness. She wrote, “The more I study human beings in the face of death, the more I learn about life and its ultimate mysteries” (p. xvii). Kubler-Ross (1983) learned about death and dying from interviewing terminally ill patients, both young and old. Her books are filled with letters, interviews, and insights from those patients. Kubler-Ross seems to model by example that death and grieving are understood by immersion into the lives of those who have lost someone to death and who then suffer grief.

Kubler-Ross (1969) described the grief process through identifying five different stages that people experience when they realize they are dying. She wrote that these stages will last for different amounts of time and that people can experience them in and out of sequence, and even in coinciding stages (Kubler-Ross, 1969). Years later, researchers Holland and Neimeyer (2010) conducted empirical research testing the stage theory of grief. The participants had experienced the death of a friend or family member within the past two years. The goal of the research was to examine the peaks and valleys of grief experienced by the participants, and also to look for ways that the individuals had created meaning within their experience of loss. Whereas the stage theory view of grief provides a high overview of the process towards understanding loss, the creation of meaning from a loss is a highly individualized process which is directly influenced by the person's own story (Holland & Neimeyer, 2010). The researchers found no strict sequence of stages that a bereaved person experienced. They did find, however, that the participants seemed to go back and forth between distress and acceptance, although no specific rhythm or predicted time indicated when they experienced one more than the

other (Holland & Neimeyer, 2010). Though the stage theory was not evident in their results, the researchers commented that a stage theory of grief still appeals to people in general who most likely seek patterns during one of life's most difficult time, those of loss and grief. It may comfort people to know what they might expect to experience in the unknown turmoil of a loss (Holland & Neimeyer, 2010). The researchers also found that participants who reported higher levels of making meaning of their loss experienced higher levels of acceptance.

Meaning making in grief. Upon partnering with many different researchers, Robert Neimeyer focused on the role of meaning making in bereavement and grief experience (Gillies & Neimeyer, 2006; Keesee, Currier, & Neimeyer, 2008; Lichental, Currier, Neimeyer, & Keesee, 2010). According to Gillies & Neimeyer (2006), after considering a variety of theories that helped clarify meaning making, three main actions were included in a meaning-making response to loss: *sense making*, *benefit finding*, and *identity change* (p. 36). Sense making takes place when the bereaved questions why the loss occurred. Why did it happen? This question is central to helping people make sense of bereavement (Gillies & Neimeyer, 2006), and it is commonly framed in philosophical or spiritual terms (Holland, Currier, & Neimeyer, 2006). Benefit finding consists of the act of "building new meaning structures" (Gillies & Neimeyer, 2006, p. 37). According to Holland, Currier, & Neimeyer (2006) benefit finding refers to the ability to find something good that has come from the loss. The researchers describe it as "the survivor's ability to uncover a 'silver lining' in the personal or social consequences of the loss" (p. 176). Identity change typically happens for people who have responded to loss in an adaptive way. Individuals report experiencing more resilience, independence,

confidence, greater awareness, more empathy, and emotional closeness to others (Holland et al., 2006).

Of the three types of meaning making – sense making, benefit finding, and identity change – the two that have been most researched are sense making and benefit finding (Holland, Currier, & Neimeyer, 2006; Lichtenthal, Currier, Neimeyer, & Keesee, 2010; Davis, Nolen-Hoeksema, & Larson, 1998). According to Gillies & Neimeyer (2006), some view identity change as the outcome of sense making and benefit finding rather than as its own way to create meaning. Subsequently, much of the research that Neimeyer conducted specifically focused on sense making and benefit finding (Keesee, Currier, & Neimeyer, 2008; Lichtenthal, Currier, Neimeyer, & Keesee, 2010).

Keesee, Currier, & Neimeyer (2008) conducted research about benefit finding and sense making as they influence grief severity. The researchers found that participants who were unable to make sense of their loss experienced greater intensity of grief. Only 14% of parents reported an ability to make meaning or sense from their child's death. The participants who were able to find meaning experienced a less intense grief than the participant's who did not find meaning or sense in the death of their child (Keesee, Currier, & Neimeyer, 2008).

Continuing the research on meaning making, Lichtenthal, Currier, Neimeyer, & Keesee (2010) conducted a mixed methods research study to identify sense making and benefit finding among bereaved parents. The majority of the participants were mothers, and the causes of death of the children spanned miscarriages, accidents, suicides, homicides, and illnesses. The children had been deceased an average of six years, and the mean age of the children when they died was 17 years old. The researchers also

compared the severity of grief symptoms to the parents' ability or lack of ability to create meaning through sense making or benefit finding.

Lichtenthal et al. (2010) found that the majority of the participating parents responded that they found no sense or benefit from their loss. However, 14 sense making themes and 18 benefit themes occurred in the other participants' responses, and these included themes of death as God's will, the existence of an afterlife, and recognition that their children were no longer suffering. The most common benefit finding theme was the parent's ability to relate to and help others who have also experienced loss. They added to this relational benefit an increase of compassion or sensitivity, enhanced spirituality, and greater appreciation of life. The researchers found that the parents who found no sense of meaning or benefit regarding the death of their children had higher levels of normative and maladaptive grief, and were more likely to be suffering with prolonged grief disorder (PGD). Symptoms of PGD include feeling that life is unfulfilling, empty, or meaningless since the loss; the parents who reported these symptoms reported feeling confused about their role in life or about their identity (Lichtenthal et al., 2010).

One of the most significant findings in the research by Lichtenthal et al. (2010) was that when parents had used their pain and to help other bereaved parents, it resulted in their own decreased PGD symptoms. According to the researchers, "Individuals whose priorities change following a death may move towards living more meaningful and authentic lives that bring fulfillment even in the face of the profound pain that results from the loss of a child" (Lichtenthal et al., 2010, p. 807).

Positive aspects of grief. Most of the existing grief research focuses on the negative outcomes of losing a loved one. According to Riley, LaMontagne, Hepworth, &

Murphy (2007), little research has been done to identify coping skills and dispositional factors that positively influence a parent's grief response to the loss of a child. The research on the loss of a child and its effect on parents include depressive episodes, health problems, and marital problems (Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008). Researchers have found that mothers who lose a child experience ambivalence to personal mortality, suicide ideation, and desire for death (Harper, O'Connor, Dickson, & O'Carroll, 2011). Even four of the five stages of Kubler-Ross's (1969) grief model have negative overtones: denial, anger, bargaining, and depression. According to Kubler-Ross (1969), only at the end of the grief stage will the bereaved person find some degree of acceptance.

In contrast, Riley et al. (2007) conducted research about optimism, coping, and social support as they relate to bereavement outcomes. They found that higher optimism in mothers correlated with their lower levels of grief responses. For example, more optimistic mothers experienced less frequent intrusive images, yearning and searching behaviors, disbelief, numbness, and poor health outcomes than did less optimistic mothers (Riley et al., 2007). They further found that mothers who coped by using planning, direct action, and problem solving experienced lower levels of grief responses than those who did not. Social support also contributed to decreased levels of grief reactions: people who shared their experiences with others had better bereavement outcomes (Riley et al., 2007).

Joan Berzoff (2006) has studied the many complexities of death and dying, and she directs the End of Life Certificate program at Smith College School for Social Work. According to Berzoff (2006), grief can lead to changes in the mourner including shifts in

self-concept, character, identity, ideals, values, coherence, perspective, and commitments (p. 126). In 2011, Berzoff wrote an article discussing Freud's and Loewald's views about the transformation a mourning person goes through. Freud's view of death and mourning changed often throughout his career, although because his daughter had died he recognized the continual bond parents feel with their children even after permanent separation (Berzoff, 2011). According to Berzoff (2011), the bereaved unconsciously take on a part of the person whom they have lost, potentially changing themselves forever, for good or bad. Berzoff (2011) also discussed Loewald's view of death and loss and concluded that, "mourning offers an opportunity for change" (p. 266). Berzoff (2011) noted multiple examples of people who had lost family members and who, in response to the loss, had created change in their community. Berzoff (2011) wrote:

These mourners are engaging in processes that allow the deceased to live on in a way that serves the social good through activities that bear witness and prevent others from having to endure the same kind of loss. That is, these mourners' ideals are shaped by the nature of their losses. (pp. 266-267)

Berzoff (2011) suggested that mourners might not consciously recognize the lessons learned from the loss, but that on an unconscious level they stay attached to their deceased loved one. She wrote that "losses may be lasting gifts; they may leave legacies in the form of acts of altruism that lead to creative changes in self and identity" (p. 267). In her conclusion, Berzoff instructed mental health professionals to encourage mourning clients to share their stories and to think of ways to build legacies. Similarly, Vail, Juhl, Arndt, Vess, Rourledge, &

Rutjens (2012) found that the conscious awareness of mortality can be motivating towards a better quality of life which includes enhanced physical health, and re-prioritized meaningful goals and values, as well as increased environmental concerns or compassion, building positive relationships, and helpful community involvement.

Researchers Greeff, Vansteenwegen, & Herbiest (2011) conducted a study identifying many aspects of resilience among grieving parents. They found that support from the community, as well as other extended family members and friends, was an important piece to adaption (Greeff et al., 2011). In the study, the parents' ability to find meaning in the situation or problem correlated positively with such adaption, especially when the family believed they had adequate coping strategies. Religious or spiritual support significantly emerged in the data as an important external coping strategies. Overall the researchers focused on the noteworthy finding that family hardiness – a family's feeling of control over life events and difficulties – influences the family's ability to adapt and recover from the death of a child (Greeff et al., 2011).

Parental grief and pediatric cancer. Research has found that the death of a child is one of the most painful experiences an adult can have (Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008; Robinson & Marwit, 2006; Harper, O'Connor, Dickson, & O'Carroll, 2011; Riley, LaMontagne, Hepworth, & Murphy, 2007). According to The American Cancer Society (2013), childhood cancers are rare and represent only one percent of all new cancer diagnoses. According to Ward, DeSantis, Robbins, Kohler, & Jemal (2014):

An estimated 10,450 new cases of cancer and 1350 cancer deaths are expected to occur among children (those aged birth-14 years) in 2014, and an additional 5330 new cases of cancer and 610 cancer deaths are expected among adolescents (those aged 15-19 years).” (p. 84)

According to the National Cancer Institute (2008), cancer is the leading cause of death by disease among U.S. children who are 1 to 14 years of age.

The topic of parents who have experienced the death of a child due to pediatric cancer has been well researched (Grinyer, 2012; Alam, Barrera, D’Agostino, Nicholas, & Schneiderman, 2012; McCarthy, Clarke, Ting, Conroy, Anderson, & Heath, 2010). Welch, Mannix, Boergers, Jelalian, Barbosa, Fujii-Rios, & Forman (2012) conducted a qualitative study on the unique bereavement of parents who have experienced the death of a child from cancer. The researchers’ goal was to learn whether parents and families would benefit from in-home visits from the oncology team that had treated the child (Welch et al., 2012). They received positive responses to the idea, and the participants’ comments revealed common themes about the bereavement process. Welch et al. (2012) noted the multiple, unresolved needs in the bereavement process of parents who have lost their children to cancer. Because the families have often experienced lengthy hospital stays with their children, they may sense further loss when they no longer have contact with doctors and staff who had been so intimately involved with their children’s treatment. The researchers found that parents, after their children’s deaths, most wanted to speak with the staff about the emotional aspects of grief rather than the medical details (Welch et al., 2012).

Alam, Barrera, D'Agostino, Nicholas, & Schneiderman (2012) also conducted research on the experience of losing a child to cancer. The researchers questioned, "How do mothers and fathers grieve and adjust to the death of a child to cancer 6 to 18 months later?" (p. 4). Six emerging themes were found in the study: (a) employment attitudes, (b) grief expression, (c) coping with grief and bereavement, (d) relationship with surviving children, (e) communication with spouse, and (f) relationship with other family members. The researchers found that the majority of fathers continued to work after the child had been diagnosed with cancer, and the majority of mothers stopped working or went to part-time and were the primary caregivers for the child (Alam et al., 2012). After the death of the child, the data revealed that the majority of mothers re-prioritized work and spent more time taking care of their other children and managing life. The fathers went back to work after the death of the child; however, some reported a loss of interest and motivation at work. One father reported that he wanted to do more "meaningful work or work honoring the memory of the deceased child" (p. 8). This father was helping with a bikeathon dedicated to the memory of his daughter, and he said that if someone gave him a million dollars, "I would be out of [work place] so fast...I'd just spend the rest of my life doing this stuff" (Alam et al., 2012, p. 8). Overall the researchers found that the mothers were less likely to return to work full time, and fathers did return although the motivation and interest in work decreased significantly after the death of the child.

Alam et al. (2012) found that fathers preferred to grieve more privately and less intensely than the mothers. Some of the mothers reported even wanting to die so they could be closer to their child. After 18 months had passed, the mothers had generally gained a better control over their grief expression, and the fathers had become more

comfortable in their expression of grief (Alam et al., 2012). Coping strategies six months after the death of their child included talking or remembering positive memories, faith in God and praying, spending time with family, keeping busy with work, and journaling. After 18 months, a new way of coping emerged: building the deceased child's legacy. To do so, parents gave their children's belongings to others, raised money for research to find a cure for the specific type of cancer that had taken their children, or created something in honor of the child (Alam et al., 2012).

Connecting with the surviving children emerged as a theme from the data collected by Alam et al. (2012), which found that taking care of the surviving children is an important coping strategy. After 18, the mothers continued to spend more time with the surviving children, although the fathers seemed to have a more difficult time connecting with them. In regards to the spousal relationships, after 18 months, many parents (40%) reported that their relationship had improved since the death of their child, whereas some parents (17%) still reported a strained relationship. The marriage relationships shifted and changed due to the life altering experience of losing a child (Alam et al., 2012).

According to Alam et al. (2012), after the first six months, the majority of mothers and fathers reported that the relationship with extended family was a critical aspect of their grieving process. A small group of parents described a strained relationship with extended family members. After 18 months, the parents recounted that extended families had grown a bit more distant as time went on. Overall, Alam et al. (2012) found that parents who were more involved in the care before the child died and those who were more open with grief expression during the first six months were better

able to connect with surviving children and were more likely to move forward with life following the death of their child than were parents who performed less care for their ill child.

The research discussed above gives an overview of death and the grief process, meaning making in grief, positive aspects of grief, and parental grief due to pediatric cancer. The literature is lacking in research about how the establishing of a foundation or charity in honor of a child impacts that person's grief. Due to this gap in the literature, there seems to be a need for further research in this area.

Significance of the Study

According to the National Center for Charitable Statistics (NCCS), there are over 1.5 million nonprofit organizations in the United States (2013). There are The Salvation Army, The Susan G. Komen for the Cure, United Way, and World Vision to name a few. While grief is a commonly researched and discussed topic, there is not research that I was able to find, about whether starting a foundation or charity in honor of a deceased child has been helpful to the parents.

The present study reveals important potential implications for mental health professionals who counsel individuals, groups, and marriage partners in grief and loss. The findings of this study could help inform clinicians to encourage bereaved clients to seek involvement in a foundation or charity in honor of a deceased child. The findings could also identify circumstances when such involvement may be more harmful than helpful.

Research Questions

The research question used for this study is as follows: How does establishing a foundation or charity honoring a deceased child influence the grieving process for the parent of the deceased child? Supporting the main research question were the following sub-questions:

1. What was the primary participant's experience with grief that led to starting Ben Towne Foundation?
2. What was the focus group's experiences with grieving and being involved with charities/foundations? How did their experiences inform the primary participant's experience?
3. What is the iterative relationship between grief and charitable work, and how did the primary participant experience this relationship regarding meaning making and identity formation?

Limitations and Assumptions

This study was an interpretative phenomenological analysis (IPA) single case study. There was one primary participant who experienced the death of her son to pediatric cancer and in response established a foundation that is researching for a cure. I used four sources of evidence to gather data: (a) semi-structured interviews with the primary participant, (b) observations in a variety of contexts, (c) documents written by the primary participant, and (d) a focus group interview with four women who had also experienced death of a child.

Limitations. The one participant sample size is my primary limitation. I chose to do a case study within an Interpretative Phenomenological Analysis (IPA), and this methodology allowed me to use only one participant; however, it does limit the applicability of the findings, which while they lead to future research, because of the limited scope cannot be generalized to the public. A second limitation was the potential for researcher bias. Because I have known about the participant and her story for the past four years, I cannot help but have preconceived ideas about the participant's lived experience.

Finally, time spent with participants is also a limitation because I did not fully immerse myself into the everyday life of the participant. As the researcher, I spent time with the participant through interviews and other observations, although it was not for an extended time period.

Assumptions. One assumption in this study was that my chosen methodology, a case study within an IPA, would help me better understand the lived experience of the primary participant. As the researcher, I also assumed that the participant would be able to provide a rich data sample. She could only elaborate on her own lived experience which, as the researcher, I assumed would allow for enough information to provide solid findings. I also assumed that my findings from the primary participant would yield professional advice and implications for counseling other people. I finally assumed that the foundation of Ben Towne Foundation influenced my participant's grief in some way. I made this assumption from the little I knew about the family's story and by reading some of her blog posts before conducting the study.

Summary

Chapter One introduced the study and topic. The introduction posed some of the difficult question about the potential benefits and difficulties that parents may experience when starting a foundation or charity in honor of their deceased child. A review of both current and foundational literature related to grief came next. The literature begins with a review of classic grief author Kubler-Ross (1969, 1983) and her perspective on the process and stages of grief. Meaning making has become a significant area of research in the field of grief and the literature discusses the various findings of researcher Neimeyer and colleagues (Gillies & Neimeyer, 2006; Holland, Currier, & Neimeyer, 2006; Keesee, Currier, & Neimeyer, 2008; Lichtenthal, Currier, Neimeyer, & Keesee, 2010). Next I reviewed the positive aspects of grief via the theories of Berzoff (2006, 2011) as well as other researchers who have studied similar aspects of grief. The literature becomes more specific by including studies conducted on parents who have lost children to cancer. Next, I explained the significance of the study and the initial research questions. Finally, I discussed the limitations and assumptions of the study. Chapter Two follows with a description of the methodology used for this study.

Chapter 2

The purpose of Chapter Two is to provide the reader with information regarding the research design and the methodology used during the course of the study. This chapter begins with the philosophical worldview and purpose overview. Next, I describe the research questions and population followed by the research design and methodology plus the process and procedures for both data collection and analysis. Finally, I identify my protection of human subjects in this study and describe the credibility, validity, and reliability.

Philosophical Worldview

According to Creswell (2009), it is important for the researcher to identify his or her philosophical worldview. I used social constructivism for the worldview of this study. According to Creswell (2009), the assumption held by social constructivists is that individuals seek understanding of their worlds through lived experiences. Consequently, the social constructivist's goal is to use the participant's experience as reality. The researcher then fully immerses him or herself into the reality of the participant, experiencing life through his or her eyes (Shaw, 2010). Social constructivism as a worldview fit well with this study because the goal of the study was to learn about the participant's lived experience. The main focus of my study was to research, explore, and identify how the participant created meaning within her lived experience.

Purpose Overview

The purpose of this study was to learn whether or not creating a foundation in honor of a deceased child is helpful and healing to parents in the grieving process. To

accomplish this purpose, I also sought to better understand the relationship between grief and charity work. By researching one woman's experience, I hoped to realize how creating a foundation honoring her son had influenced her grieving process. In addition, by also researching others in the focus group, I hoped to better comprehend the cultural context in which my participant lives. My goal was also to show how these two perspectives might present possible clinical considerations regarding grief healing.

Research Questions

The research question used for this study is as follows: How does establishing a foundation or charity honoring a deceased child influence the grieving process for the parent of the deceased child? Supporting the main research question were the following sub-questions:

1. What was the primary participant's experience with grief that led to starting Ben Towne Foundation?
2. What were the others' experience with grieving and being involved with charities/foundations? How did their experiences inform the primary participant's experience?
3. What is the iterative relationship between grief and charitable work, and how did the primary participant experience this relationship regarding meaning making and formation identity?

Definition of Key Terms

Throughout this study, I frequently use the following terms:

Bereavement. “Bereavement is the objective situation of having lost something or someone significant” (Jakoby, 2012, p. 680).

Charities/Foundations. In this study, I define the terms *charities* and *foundations* in the broadest sense as any organization or effort created in honor or memory of a deceased person. Within this study’s context, the deceased was a child. This definition is broad enough to include government recognized major non-profit foundations as well as small ventures such as a child’s lemonade stand which raises money to honor a deceased person.

Coping. “Coping is related to processes or strategies of managing the situation in which bereavement places the individual” (Jakoby, 2012, p. 680-681).

Grief. “Grief is the emotional response to loss” (Jakoby, 2012, p. 681).

Meaning. In this study, meaning is defined as purpose, or significance.

Mourning. “Mourning refers to the expression or practices of grief in a given society and culture” (Jakoby, 2012, p. 681).

Population and Sample

My study’s population includes parents who have experienced the death of a child and who also have done something in memory of their child. The primary participant in this study is a mother, Carin Towne, who lost her son to pediatric cancer. After a year and a half of treatment for neuroblastoma, Ben Towne, Carin’s first-born son, passed away on December 30, 2008. Carin and her husband, Jeff, founded Ben Towne Pediatric Cancer Research Foundation in 2010 through partnering with Seattle Children’s Research Institute. Together Ben Towne Foundation and Seattle Children’s Research Institute

established the Ben Towne Center for Childhood Cancer Research. The research center opened in 2011 and focuses on developing new treatments that could eventually replace chemotherapy and radiation. The foundation raises money for the research center whose goal is to create more humane and successful treatment for the most aggressive types of pediatric cancer (Ben Towne Pediatric Cancer Research Foundation, 2014).

It was through a friendship with her sister that I learned about Carin and her experience over the past five years. Because of my relationship with her sister, I asked Carin to participate in my study and she agreed. Carin is a 40-year-old Caucasian female. After being married for 10 years, Jeff and Carin welcomed Benjamin Ward Towne into the world on July 17, 2005. Ben's younger brother, Ryan, was born on November 28, 2007, during which time Ben was already in cancer treatment. Carin has a Bachelor of Arts and a Master of Fine Arts in Acting from the University of Washington, and today she works full time with the foundation as the communications director.

In addition to Carin's major participation in this study, I used a focus group to provide supplementary context to Carin's experience. The focus group included four women ranging in age from 44 to 59, all of whom are part of a private writing group. All four women have experienced the death of a child, and have done something in memory for that child whether that be something private and/or public.

Methodology

Because of the naturalistic and emergent nature of the study, my research design was qualitative. The strategy of inquiry was Interpretative Phenomenological Analysis (IPA). According to Shaw (2010), the central goal of IPA is to "understand what personal

and social experiences mean to those people who experience them” (p. 178). Thus, IPA is an experiential research method that looks specifically at a particular person’s experience at a particular time of his or her life (Shaw, 2010). The study was an individual case study within a phenomenological methodology.

Within the IPA strategy, the researcher is an active part of the research process. As the researcher asks the primary and secondary participant to interpret and make sense of their environment, the researcher also analyzes and makes sense of the participants’ testimonies, thus engaging in a process of double hermeneutics (Shaw, 2010). Johnson (1997) describes this process as, “The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world” (p. 53). IPA researchers are actively aware of their dual roles as collector and interpreters of the information. Due to the idiographic nature of this method, it is appropriate to use just one individual participant (Shaw, 2010). According to Johnson (1997), IPA studies are typically small in sample size because the goal of the study is not to make generalizations, rather the goal is to, “say something in detail about the perceptions and understandings of this particular group” (p. 55).

Data collection. I used four sources of evidence in this study: (a) in-depth interviews, (b) focus group, (c) documents, and (d) observations. Each of these sources was used to collect data. Below the process of how I used each source of evidence is described.

In-depth interviews. I interviewed my primary participant four separate times, and used a semi-structured interview procedure each time (see Appendix A for interview guide). All interviews took place at the participant’s home at a convenient time for her,

typically during a weekday between 1:00 p.m. and 3:00 p.m. At the beginning of the first interview, the participant signed the informed consent form (see Appendix D for informed consent for primary participant), and I reviewed with her the potential risks of the interview and reiterated that she did not have to answer any questions that made her uncomfortable. I also explained the outline for the interviews, detailing for her the themes and goals for each interview. At the beginning of each interview, I asked about her feelings and emotions, and I repeated these questions before I left. I audio recorded and transcribed each interview, and each lasted between 90 and 120 minutes. The interview transcripts yielded 102 total pages, ranging from 19 to 34 pages per interview.

Focus group. I conducted the focus group to learn about the other women's experiences of losing children and dealing with grief, experiences similar to Carin's (see Appendix B for focus group guide). Carin provided me names of these focus group participants. Carin also introduced me to her friend whose daughter died from pediatric cancer. That friend is a part of a writing group of bereaved mothers. I inquired if I might interview all of them at a group meeting, and they each gave consent.

The focus group members in the group, all females, ranged in age from 44 to 59. I attended the group meeting on a weekday evening. I began by briefly explaining my dissertation and assured them that their participation was voluntary, that at any time they could discontinue. Each of the women signed an informed consent form (see Appendix D for informed consent for focus group members). Next, I asked each woman to state her name, her deceased child's name, his or her death date, and to explain and describe if they had done something in memory of their child. Open-ended questions then gave me feedback about some initial themes from my primary participant's interviews. The focus

group lasted an hour and each woman had significant time to share. The cause of death for each child was different: one participant's daughter died at 12 years old from pediatric cancer. One participant's son died of a virus that attacked his heart at 21 years old. One participant's baby was born pre-term at 23 weeks gestation; she lived for just 10 minutes. Lastly, one participant's son died from a work accident where he fell 80 feet from a crane at 28 years old. Although the members of the focus group could not speak to Carin's personal experience, they provided me insight into the culture and population of which Carin is a part, and ultimately help to understand her experience at a deeper level. I also audio-recorded and transcribed this focus group meeting.

Documents. Carin wrote a blog throughout the time of Ben's diagnosis, treatment, and death. The blog, 158 pages, is public and printed. I read through the entire document three times. On the final read, I wrote memos and created codes for themes. I also read the Ben Towne Foundation's current blog and studied its website to learn more about Carin's personal experience of grief as well as with the Ben Towne Foundation.

Observations. I gathered my observations (see Appendix C for observation/field notes form) in three ways: at the home of the primary participant, at a tour of The Ben Towne Center for Childhood Cancer Research, and at the annual Ben Towne Foundation benefit in September 2013. Observations purport to help me, the IPA researcher, discern more about Carin's world and about its impact on her grief and on her involvement in Ben Towne Foundation. My observation notes were derived from my interpretations of precisely what I was observing, and I used these observation notes to support the emerging themes from the data.

The first observation experience was at the annual Ben Towne Foundation benefit on September 27, 2013. As a guest at the benefit, I took notes of my observations as well as of the content of the different speeches delivered. My second observation took place in Ben's own bedroom. Carin allowed me to look around, and she pointed out some special items there. Finally, on April 1, 2014, I took an official tour of the Ben Towne Center for Childhood Cancer Research. Carin, her husband Jeff, and Dr. Michael Jensen hosted this tour for 15 people, each interested in learning more about Ben Towne Foundation. It began with a short introduction regarding the future of treating childhood cancer. We then toured the Ben Towne Center for Childhood Cancer Research and saw its research laboratories. At the end of the tour, Dr. Jensen offered a Q&A, and Carin shared a story about Ben. I used my tour to support the emerging themes from the interviews and documents.

Data analysis process and procedures. I analyzed each of the sources: interviews, focus group, documents, and observation notes. In regards to the interviews, I audio-recorded and transcribed each one. Next, I studied each interview numerous times specifically for overall meanings and insights, and I then coded these for themes. I created an excel spreadsheet for each interview and recorded the emerging phrases or words there. Next, I similarly combined words and phrases to reveal overall themes emerging from the data. After conducting this process for each interview, I combined coded themes from the four interviews into one spreadsheet.

I used two different blogs for data. The first, Ben's blog (2007-2008), was the primary participant's, written during the time of Ben's diagnosis, treatment, and death. This public blog is located on Ben Towne Foundation's website. The second blog (2014)

was the current website of Ben Towne Foundation. The primary participant has continued to write some personal posts, as well as updates about Ben Towne Foundation. I read Ben's blog in its entirety twice, then on the third time I coded for themes. The second blog I read and then used the personal posts in the data to support coded themes after triangulation.

The focus group interview focused on some of the emerging themes that had come from interviews with the primary participant: the lived experience of a parent who loses a child to death, meaning making in grief, and the idea of response to the death of a child. I audio-recorded and transcribed the focus group interview and then read it thoroughly to discern emerging key phrases and themes.

Finally, I typed the observations notes and read them carefully to identify themes and insights, which I then used to support the triangulated data. The observations offered me a fuller view of the primary participant's life. The annual benefit, tour of The Ben Towne Center for Childhood Cancer Research, and visiting Ben's room individually and collectively gave insight and support to the overall themes that emerged after triangulation.

Triangulation interweaves the three sources of evidence: interviews, focus group, and documents. According to Patton (2002), triangulation helps strengthen the study by diversifying the perspectives of a phenomenon as well as increasing its credibility. For this study, I have used one of Patton's (2002) four types of triangulation. I triangulated between sources to help identify any consistency or discrepancy of different data sources. As Patton (2002) described, the data did not all point to a single theme or pattern; however, triangulation seeks to understand why and when any data differences occur.

A second coder – research assistant – confirmed or refuted the existence of the themes found in the interviews. I gave the second coder only the interviews because they were the major portion of the data collected. I fed the themes that had emerged from the data to the second coder who then specifically read for theme agreement and sought for themes I had missed or overlooked. The second coder and I then met to analyze the results. The second coder agreed with my listed themes, and we then discussed answers to the main research question including whether the Ben Towne Foundation has been helpful for the primary participant's grieving process. Following this discussion, I again reviewed and then updated our concluding thoughts.

I also presented these findings to the primary participant and asked if she felt the themes were congruent with her lived experience. I met with her in her home, she read excerpts, and then I presented the research questions and up-to-date answers to her. We met for this discussion twice, and each time I made minor changes.

I formatted the findings as answers to each of the research questions and found it a practical way to use the various themes that had emerged from the data. It gave the findings a clear relationship to my crucial questions and therefore made it easier to understand how the findings actually answered the research questions.

Credibility, Validity, and Reliability

According to Patton (2002), the following measures can be taken to increase research credibility: education, experience, and perspective. Regarding education, I have specific education and training in conducting qualitative research at both the master's and doctoral levels. Regarding experience, I am a counselor and have previously worked in a

private practice as well as currently in a clinical internship experience. In both instances, I have worked with people suffering from loss. Regarding perspective, I have not personally lost a close family member; however, I still have preconceived notions regarding the experience of grief. I have known of my participant since January 2009, when I met her sister through mutual friends. I have heard over the past few years about Ben's story, and I have also read many of Carin's blog entries over the past few years. I have met Carin personally on only two occasions before starting this study, and I attended the 2011 Ben Towne Foundation Benefit.

To increase research validity, I triangulated between sources and clarified the bias of the researcher (Cresswell, 2009). Johnson (1997) also discusses strategies used to increase validity in qualitative research methods. According to Johnson (1997), "Interpretive validity refers to accurately portraying the meaning attached by participants to what is being studied by the researcher" (p. 285). Also according to Johnson (1997), one of the most important strategies to increase interpretative validity is participant feedback or "member checking" (p. 285). To obtain participant feedback, I shared interpretations and findings with the primary participant to clarify any miscommunication and to learn whether or not she agreed that my findings relate to her experience. After analyzing the data and writing the first draft of findings, I presented and discussed it with my primary participant. I made a few minor changes after the discussion.

Johnson (1997) also discussed the strategy of using low inference descriptors to obtain the most accurate portrayal of the participant's experience and voice. Johnson (1997) reports that the best way to accomplish this interpretive validity is to use direct quotations, which I have done via audio-recordings and transcriptions.

To increase reliability of the study, I used a second coder for intercoder agreement as well as for documenting the detailed procedures (Creswell, 2009). Yin (2009) agrees that researchers should document the case study procedure in detail so as to maintain reliability. By keeping closely detailed accounts of the process, I have consistently maintained research reliability.

Protection of human subjects. I provided human study protection in this case study. The Human Subject Review Board (HSRB) approved the study. Additionally, because the Ben Towne Foundation is a public non-profit organization, and because Carin Towne gave me permission to use her private name, I did not conceal the foundation title or Carin's name and personal story. I came to this decision through consulting with my dissertation chair, committee, HSRB, and primary participant, Carin Towne. Because the foundation's name includes the Towne family name plus Ben's, it was impossible to maintain Carin's anonymity or confidentiality; her name is firmly on the foundation's website as well as in her relevant blogs and other public material. Carin felt comfortable with me using her name in the dissertation. I have used my own discretion to privatize the details Carin shared that are not relevant to the research questions of this dissertation.

Because of its sensitive nature, I gave special consideration to all participants and their experiences. According to researchers Koffman, Higginson, Hall, Riley, McCrone, & Gomes (2012) who conducted research exploring the appropriateness and acceptability of using bereaved relatives of deceased cancer patients, it is acceptable for research purposes. I continually checked in with my primary participant before and after the interviews to make sure she was as comfortable as possible in telling her story. I assured

both the primary participant and focus group members that they could stop at any time and that they did not have to answer any questions they did not feel comfortable answering.

I sent the interviews and the focus group interview to a transcription service to be transcribed and upheld security and confidentiality in the entire process. As I collected the data, I secured it to insure privacy and confidentiality. Additionally, the primary participant and focus group members signed informed consent forms (see Appendix D for informed consent forms).

Summary

This chapter began with the philosophical worldview and purpose overview of my case study. Next came the research question and a description of the population and the sample followed by the research design and methodology plus the process and procedures for both data collection and analysis. Next, I detailed my methods used to increase research credibility, validity, and reliability. Finally, I explained my human subject protections procedures.

Chapter 3

The purpose of Chapter Three is to describe for the reader the findings which resulted from the data gathering during the course of the study. This chapter includes the research findings that emerged from the data. I have located the findings with the appropriate research questions, which I have answered in the following order:

1. What was the primary participant's experience with grief and with starting Ben Towne Foundation?
2. What were the others' experience with grieving and being involved with charities/foundations? How did their experiences inform the primary participant's experience?
3. How does forming a foundation to honor a deceased child influence the grieving process for a parent of the deceased child?
4. What are the iterative relationships between grief and charitable work, and how did the primary participant experience this relationship regarding meaning making and identity formation?

Question 1

The first question asked was, "What was the primary participant's experience with grief and with starting Ben Towne Foundation?"

September 10, 2010, the launch and kick-off of Ben Towne Pediatric Cancer Research Foundation is underway at the Seattle Sheraton Hotel. The band plays cocktail music as people mingle and enjoy appetizers and drinks. The room is filled with laughter and chatter. She stands confident and poised in front of the large audience before her,

speaking words of hope and inspiration. “We invited you here tonight in the hope that you might join us, that you might dig deep, that you might dream big, that you might envision a world where all childhood cancers have cures. But we cannot do it alone.”

(Vimeo, 2012) That evening, \$525,000 was raised and donated to the foundation’s partner the Ben Towne Center for Childhood Cancer Research to help further research cures for pediatric cancer (Ben Towne Pediatric Cancer Research Foundation, 2014).

Hours later she is alone, standing in her son’s empty room, longing to see him, hold him, smell him. The laughter and chatter are still ringing in her ears, she feels anger, and reality hits hard: if Ben were alive, tonight would not have happened (C. Towne, personal communication, November 20, 2013).

On July 17, 2005, Benjamin Ward Towne was born to Carin and Jeff Towne. He was born healthy and happy, with a stubborn and funny personality. Then, in August 2007, his parents noticed a discoloration around his eyes which they first thought to be an allergic reaction. However, Ben soon became sick. He was extremely fatigued and sick to the stomach. After a blood test at the pediatrician’s office, doctors recommend they take Ben immediately to Seattle Children’s Hospital ER. And Carin then experienced her first wave of terror, knowing instinctively that something was dreadfully wrong. On August 16, 2007, Carin and Jeff heard the life-changing news: “Your child has cancer.” Ben went through many tests -- blood work, biopsies, bone marrow aspirate, CT scan, MRI, and X-rays -- to learn the correct diagnosis. As a result, Ben was diagnosed with stage four neuroblastoma and began treatment immediately. He was hooked up to a morphine drip to ease the pain, and Carin suddenly realized how much pain he had been in because he perked up and seemed himself again. On Monday, October 20, 2008 – just a year and two

months later – Ben, now three, had endured six rounds of chemotherapy, surgery to remove the tumor, a stem cell transplant, twelve sessions of radiation, twenty antibody infusions, and six courses of oral medications (C. Towne, Ben's blog, October 20, 2008). On November 2, 2008, scans revealed that the cancer had aggressively returned leaving Ben with four new tumors, three on his brain and one on his liver. At this point, all hope for his life was lost. Carin and Jeff took Ben home. On December 30, 2008 Benjamin Ward Towne passed away in the comfort of his home (C. Towne, personal communication, November 20, 2013).

Carin's grief experience. Carin's experience with grief was and continues to be complex, in no small part because of the intensity of Ben's treatment experience. From the moment he was diagnosed, Carin recalls moving into survival mode:

First you feel an intense amount of adrenaline, but it's a different type of adrenaline. It's like terror, and it's coursing through your veins. You alternate between some sort of insanity. You think, "Three days ago I was sitting at my own house watching whatever reality TV show was on, and now I'm living in the hospital." My son is hooked up to an IV; he's had surgery to put a tube into his jugular vein. It is like a pendulum swing, you feel like any second you'd wake up, and it would all be a bad dream. (C. Towne, personal communication, November 20, 2013)

Carin describes a pre-anticipatory grief that she experienced when she realized that Ben was going to die:

During the second week of December, he started slowing down. And then it was this restart of my pre-anticipatory grief. It's like, "This is really going to happen; he's going to leave." (C. Towne, personal communication, November 20, 2013)

Immediately following Ben's death, Carin experienced pain and suffering from being separated from her son. She described how it felt physically:

It [grief] was so intense, I honestly thought I was having a heart attack. My whole body was sweating and shaking, I can't breathe – I'm heaving. My heart is beating so fast. Those first few weeks were like being caught in an undertow you couldn't get out of, I was literally drowning." (C. Towne, personal communication, November 20, 2013)

You can't get closer than to your own biological child, and that physical separation makes you physically crazy...you're just completely out of control. You can't control the way your body is responding. It aches. It shakes. Your heart beats super-fast. It comes on like you can't breathe. You're trying to – you're gasping all the time when you have a wave of it. (C. Towne, personal communication, January 21, 2014)

During the weeks that followed, Carin was having difficulty functioning in her everyday life. She had great support from her family, yet she felt a distance from herself.

I felt like I was not present here. I know I would get up and I would go for a walk in the morning, which had been my routine my whole life. I know I did that. I know I showered...and then I don't, I don't know what happened in those days. (C. Towne, personal communication, November 20, 2013)

At moments the pain was so intense and the longing to see her son so painful that she considered taking her life simply to be with him. She explains:

I would be lying if I didn't tell you that there were many days that I considered not being present here. I believe that Ben is somewhere else and there is a huge part of me that just wants to go to that place. It's a very different type of suicide cause it's like I believe God has my child and I want to be there, and this is the only way. I can't get there unless I leave here. (C. Towne, personal communication, November 20, 2013)

In time, Carin realized that having a routine was helping her cope. The reality that she had no control created a need to find what she called a "false sense of control" (C.

Towne, personal communication, January 21, 2014), and this came in the form of a daily routine:

Being schedule-oriented has been a huge coping factor for me, I think...part of the management has been that we [Carin and Jeff] finally realized that we just needed to do the same thing every day and not divert from it...the routine carries you, it is a structure to lean on...it is helpful because if you do the same thing every day, it just sort of carries you to the next day. (C. Towne, personal communication, November 20, 2013)

Routine has been incredibly helpful to us. I do the same thing every morning.

Rain or shine, I am walking or running. The only time not is if I'm traveling and it's not possible. I get up. We do things in the same order. (C. Towne, personal communication, January 21, 2014)

Starting Ben Towne Foundation. The experience of Ben's diagnosis, treatment, and death left Carin and Jeff stunned and bereaved. Life as they knew it would never be the same. The experience of watching their son be treated for and die from cancer permeated every aspect of their lives. To walk away from the cancer world seemed impossible. Carin reported, "We went into the world of cancer with our son, and then he left us there" (C. Towne, personal communication, November 20, 2013). Jeff went back to work, though only for a short time; it was difficult to return to anything that had once been normal in a world where everything had changed and would never be the same.

The Towne's had the opportunity to walk away from life for a few months, so they packed up their son Ryan and stayed at a family cabin. But the escape would not last forever, and they had to pick up real life sooner or later.

During the time of Ben's treatment, Carin's mother had started a fund at Children's hospital for neuroblastoma research. After Ben died, the family asked that donations be made to this fund in lieu of flowers. The fund grew quickly, and after Ben's death the Towne's wondered what to do with it. However, soon they were approached about an opportunity to start a foundation. After talking it over with trusted family and considering the potential effects it would have on their son Ryan, the Towne's decided to move forward with the opportunity. As Carin remembers, "I think once we started talking about it, it sort of seemed like, "Why wouldn't we do it? We don't have a clear sense of what's next" (C. Towne, personal communication, December 2, 2013).

As they took the steps necessary to move forward, doors opened and they met Dr. Michael Jensen who was being recruited by Seattle Children's Hospital to start a new pediatric-based cancer research program in Seattle. After their meeting with Dr. Jensen, it

was clear that they wanted to partner with him and his vision for a world where the treatment of pediatric cancer was very different:

We realized very quickly after meeting Mike [Dr. Jensen] that his research is exactly what we wanted to be funding. We wanted to fund research, and we wanted to specifically be funding a new kind of research that changes that way we treat kids with cancer. Ultimately Ben's death was the worst, but what people don't understand is because we treat kids with chemotherapy and radiation, there are losses along the way. You're grieving all the time along the way. (C. Towne, personal communication, December 2, 2013)

Dr. Jensen is now the director of Ben Towne Center for Childhood Cancer Research at Seattle Children's Research Institute as well as professor of hematology-oncology at the University of Washington School of Medicine. Dr. Jensen's research is groundbreaking and "will radically change the way doctors treat and cure pediatric cancer patients" (Ben Towne Pediatric Cancer Research Foundation, 2014). Though the Towne's did not know much about starting a foundation, they did know a lot about pediatric cancer. Carin said, "We didn't know anything about how foundations run. That part was really overwhelming. The actual cancer part; we know more about cancer than most people. Sadly, we are experts on childhood cancer" (C. Towne, personal communication, December 2, 2013).

For six months, the Towne's worked the business and administrative sides of establishing the Ben Towne Foundation. They also solidified the Ben Towne Foundation's relationship with Children's Research Institute and worked toward giving

their message a meaningful title, so naming it Ben Towne Foundation was an important part of the process:

Our full name is Ben Town Pediatric Cancer Research Foundation. And we were very specific in our naming at the beginning because there are so many foundations out there that do everything, anything, all things. And we want to be very clear in our title. We are pediatric cancer research. We're not family-centered care. We're not uncompensated care. We're going after research. That's it. (C.

Towne, personal communication, January 21, 2014)

After a lot of hard work, Ben Towne Pediatric Cancer Research Foundation was launched on September 10, 2010, at its first annual benefit for pediatric cancer. Since then, Ben Towne Foundation has donated over \$4 million dollars to Ben Towne Center for Childhood Cancer Research at the Seattle Cancer Research Institute (Ben Towne Pediatric Cancer Research Foundation, 2014). According to Ben Towne Foundation website, the focus is clear:

The focus of the Ben Towne Center for Childhood Cancer Research is to discover then develop innovative new targeted therapies for curing childhood cancers – eventually reducing or eliminating the need for surgery, chemotherapy and radiation treatments. Initially, the team will continue their promising research on T cells, a type of white blood cell in the immune system that protects the body from infection. Since cancer cells start out as healthy cells, T cells don't recognize them as threats. Dr. Jensen, the Director of The Ben Towne Center for Childhood Cancer Research, and his team are working to reprogram the body's infection-fighting T cells to seek out and destroy cancer cells wherever they are hiding in

the body. This therapy can be applied to all types of childhood cancer. (Ben Towne Pediatric Cancer Research Foundation, 2014)

Since the 2011 establishment of The Ben Towne Center for Childhood Cancer Research, two cellular immunotherapy clinical trials using reprogrammed T cells have been FDA approved. In 2013, the first two cancer patients to receive T cell therapy via these Phase 1 clinical trials had positive responses (C. Towne, personal communication, May 5, 2014).

Current state of grief. Carin reported that, as time progresses, her grief feels more manageable. The separation from Ben does not get easier, but she has learned to live with it and understands now more about how her body and emotions react to her grief. Though time has made it more manageable, Carin reports that life is darker now that she is separated from her oldest son:

Here's what happens. It's like you lost some colors from your color palette and you don't get those colors back. It's cheesy but probably the really bright yellows and the really bright oranges and chartreuses are all a little bit muted now, and some colors you don't have at all. (C. Towne, personal communication, January 21, 2014)

I wish someone would have just sat me down and said, "You're not going to heal." That's really hard to hear, but it's just the truth. I just thought in the beginning, if I did everything right and was seeing my therapist and writing and reading grief books and really working hard at grieving and doing it right, it would get better. So far, five years what I've learned is – it doesn't get better. It just gets more manageable. I was wrong to think it would get better because the idea of getting better means you feel the way you did before this happened, or you

become restored to the person you were before all that happened. (C. Towne, personal communication, December 17, 2013)

Time makes you more able to bear the weight of it. You get more tools on how to handle it. You just acquire more managerial skills. You get more used to the pain.

You get more used to the way of it. You get more used to the cycles that come.

You understand what's happening. (C. Towne, personal communication, December 17, 2013)

Carin spoke about her grief feelings even five years after Ben's death and acknowledged the continual losses as time goes on. All the moments and experiences that Ben misses weigh heavily on Carin, and as family and friends thrive and children around her grow up, the reality of what could have been is at times unbearable. After my fourth interview with Carin, I asked to see Ben's room. I asked Carin to talk about the different pictures, special stuffed animals, and blankets in Ben's room. There was a yellow sticky note on one of the windows with words that read "DO NOT WASH!" I asked Carin about it. She said they had recently gotten their windows cleaned; however, it was very important to her that they did not wash this specific window because when the light shines through, you can see Ben's handprint (Observation, January 21, 2014). It is a handprint she cannot lose:

They're all losses. That's what people don't understand. You have the loss of Ben, but then you have all these losses along the way. That's one of the things people just don't get about grief. You continue to have loss all the time. It's not just the loss of him on Dec. 30, 2008. It's all the losses we have subsequently

because of his absence. Some people forget. (C. Towne, personal communication, December 17, 2013)

Here is the thing about grief: You can't go around it. You can't go over it, or under it. You just have to continue to go through it – again and again. Because despite what Hallmark wants you to believe, the losses continue. (C. Towne, blog, March, 2014)

Carin reported that even though the daily physical experience of grief has subsided, she still has moments that trigger her grief, and she is knocked off her feet. “Things will come up out of the blue and they will side swipe you. And you don't know they're coming and you don't know you're going to react that way” (C. Towne, personal communication, January 21, 2014).

So you panic while you're having a grief attack, you are also having a panic attack of “when is this going to stop? When will I be able to breathe?” Now I know. It will pass. I will come back down. But this is what it is right now. And I'm so sad. And just having a better understanding of when those kinds of grief attacks come makes me feel not so crazy when it's happening because I get it. I know it's happening. I know why I'm responding this way, and I know enough to know now that I'm going to come down from this. And it might ruin me today, but tomorrow I'll wake up. It'll be a better day. (C. Towne, personal communication, January 21, 2014)

Carin reported that one “benefit” from Ben’s death is the way she and her husband parent. Carin suspects that if Ben were still alive she would still be trying to do

everything perfectly and worry about all the little things. What is important to her as a parent has changed for the better:

We talked about the benefits of having your child die. You do gain a different perspective. I don't spend an obscene amount of time hyper-worried about how much TV Ryan watches or the content of the Mario video game. If he's happy, I'm happy. At curriculum night at school, parents were asking so many questions and worried about what their child was learning in kindergarten. I'm just happy Ryan's happy. I'm happy that he has buddies and that he's playing sports because he's healthy, and he's doing stuff that kids should be doing. (C. Towne, personal communication, January 21, 2014)

Question 2

The second question asked was, "What were the others' experience with grieving and being involved with charities/foundations? And how did their experiences inform the primary participant's experience?" The others, as referenced in the research question, are the members of the focus group. The members were all women who had each previously experienced the death of a child. Each woman had also responded to her child's death in either small or more public ways. Three main themes arose from triangulating between interviews, documents, and the focus group: (a) no meaning in death, (b) meaning in life, and (c) response to suffering. First, neither Carin nor the focus group members have been able to find meaning or make sense of the death of their children, not even through actions taken in honor of that child. Second, however, the focus group and Carin reported

that their lives did have meaning despite the death of their child. Third, Carin's response shows that Ben's intense suffering is as grief-making as is his death.

No meaning in death. The focus group data collected from the focus group revealed both similarities and differences among each participant's experience and response to the death of their child when compared to Carin's experience and response. One major agreement theme was that the participants had found no purpose or meaning in the death of their children. Even though these women had all done acts in memory of their children, these acts did not create meaning for their children's death. I asked both the focus group and Carin about this idea of meaning and the responses showed strong emotions. One focus group member spoke to this fact:

I have a pretty strong reaction to that. I do think there is way to make meaning of your life afterward. It's not a cause and effect, but it happens. You recalibrate and then you go. I have a really strong reaction to that [meaning in death] – that this is part of God's plan or something. That's just not that way I look at it. I do think people can go on and lead incredibly meaningful lives after a horrendous loss – amazingly in spite of. Humans have this resilience that is quite remarkable.

(Focus Group, April 3, 2014)

The same focus group participant stated:

There's no purpose to her death and anybody who would try to say to me that this is why it happened I would not be talking to any longer. You cannot excuse the death of a child. You can't. There is no excuse. It's just a broken system. The world is flawed. (Focus Group, April 3, 2014)

Another focus group participant stated, “That pretty much ignites fury. How can you make this [death of child] meaningful? In the same breath she [child that died] bonded us [family] all together. It opened us up to different layers of connection” (Focus Group, April 3, 2014).

Carin had a similar response when asked about meaning as it related to Ben Towne Foundation and Ben’s death:

People want to make it feel better so they look for a purpose in his death. Why should there be purpose behind my child dying and purpose in your child living? What they are saying is, “Ben was supposed to die so we could do this and change the world for other people.” But your child is supposed to live to help change the world for other people? It just doesn’t make any sense. People say, “Everything happens for a reason” or “It’s amazing to see God’s purpose in this whole thing.” This makes me feel so angry. (C. Towne, personal communication, December 17, 2013)

I don’t feel like it has made Ben’s death meaningful or made his suffering redeemed in some way. It’s been our response to his death. We are going to do something about it. I don’t believe there was a purpose in Ben’s death. Are we making our purpose? I guess in some way we are. Yes, on one hand, it’s meaningful. It’s meaningful that we could do something in his memory so that people know who he is; obviously that we care that people know him. (C. Towne, personal communication, January 21, 2014)

What they’re saying is they are trying to make you feel better about what’s happened to you. They are trying to make comfort. “Isn’t it amazing what’s

happened? You guys are doing such great work. It must feel so great to know you're doing this in Ben's honor." No, it doesn't feel great. It sucks. (C. Towne, personal communication, January 21, 2014)

Even though these women had all done acts in memory of their children, these acts did not create meaning for their children's death.

Meaning to life. According to the interviews/documents of Carin and the Focus Group members, people can find meaning in life as it moves forward, even after experiencing the death of a child. The difference between finding purpose or meaning in a child's death versus finding meaning in the parent's life after may seem slight, but it is an important difference. According to the data, these women had experienced and recognized purpose before grievous loss such as the death of a child; it is not the child's death that provides purpose in life. However, while the former purpose in life becomes severely altered and changed forever, the death of a child does not completely eradicate each individual's purpose in life, though at times it may feel that way. The experience of the death of a child may alter and change it, but purpose and meaning exists *despite* the child's death, not *because* of the child's death. Focus group members validated this assertion:

After a period of time it was like, "Oh my gosh. Life goes on." It fucking goes on even though you don't want it to in the beginning. But it does, and then all of a sudden, it's not just pure misery. I took a meditation class, I read...it was like, "Wow, this is not a bad state to be in – this feeling of gratefulness for everything we have." It was a way to make meaning in one's life. Guess what. You are here.

The last thing you want to do is curl up and die. That's the last thing your loved one wants you to do. (Focus Group, April 3, 2014)

Another focus group participant stated, "So none of those things [actions taken in memory of child] will ever outweigh the tragedy and the wrongness of it, but it gives me something worthwhile to do" (Focus Group, April 3, 2014). Carin agreed with the focus group participants, stating, "This [the Foundation] has given us a way to move forward. It's given us a way to proceed. It's given us something tangible to do with our anger and with our grief in response to what happened to Ben" (C. Towne, personal communication, December 17, 2013).

She further stated:

What everyone wants is for what we're doing to give meaning to his death and his life. Even if we do cure childhood cancer in our lifetime, and I think we will, it still doesn't change our life. It doesn't change our grief; it doesn't change how much we miss him or long for him every day. But it has given us a way to move forward, it has given us something to do. And that does not negate his suffering or his death. (C. Towne, personal communication, January 21, 2014)

It is not the child's death that provides purpose in life, purpose may come from how a person chooses to respond.

Response to suffering. There was agreement throughout the interviews, documents, and observations that though the Ben Towne Foundation allows Carin to proceed and in many ways gives meaning to her life, it in no way gives meaning to Ben's death. While Ben Towne Foundation offers her a way to respond to his death, it also

helps her immensely in response to his suffering. Carin's blog during Ben's illness and death often acknowledged his pain and suffering:

We arrived at the ER this morning around 6am. Despite our efforts to keep Ben hydrated and medicated this week – this last round of chemo has really taken its toll. Ben is severely dehydrated, continuing to throw up, his blood counts are low, and he now has a fever. He looks at us and cries as if to say, “Please make me feel better.” And there is nothing we can do except cry, pray, and hold him. It is a very helpless feeling. (C. Towne, Ben's blog, October 21, 2007)

All cancer is awful. Neuroblastoma is one of the worst. It is a deceitful, tricky, and hard to kill cancer. Basically it is sin in a cell. Because of this Ben will be receiving some of the most hardcore chemo drugs that are available – it is the only way to fight it. Yet, the side effects are dangerous and discouraging. (C. Towne, Ben's Blog, October 9, 2007)

Fall is my favorite time of year. While walking through our neighborhood this morning it seemed fall is here. The first sign that they will eventually fall, leaving the branches bare. Bare. I feel like this is what is happening to us, to Ben. We are being stripped. Stripped, of control, stripped of life, of everything we know. (C. Towne, Ben's blog, September 18, 2007)

After watching Ben experience such intense suffering, it felt impossible for Carin not to respond. She needed somehow to bring justice to this loss; she could not let cancer win without a fight. Carin spoke often about Ben's suffering, and so did the focus group member whose daughter died of cancer. Both children who died of pediatric cancer endured a significantly longer treatment than the other children represented in the focus

group. For the two mothers whose children died of pediatric cancer, the experience of their child's suffering was a significant aspect of their own experience:

I've never seen this as a fight against cancer. I felt she was ambushed. I felt she was raped. I felt she was murdered. All of those things, kidnapped, all of those things that you can't fight against. It was like terrorism. So to me, I never speak of fighting cancer. It wasn't a fair fight. (Focus Group, April 3, 2014)

Carin agreed:

It's not just about Ben's death. Yes, ultimately his death is the worst part, but what people don't understand are the losses along the way due to the current treatment options. We treat kids with chemotherapy and radiation. You are grieving all the time along the way. (C. Towne, personal communication, December 2, 2013)

She added, "I could not stop seeing those images of moments in his treatment where he's in so much pain he was beating his head on the wall" (C. Towne, personal communication, November 20, 2013).

Question 3

The third question asked was, "How does forming a foundation to honor a deceased child influence the grieving process for a parent of a deceased child?" As evidenced by the data, Carin's experience with grief and the impact of Ben Towne Foundation on that grief revealed six emerging themes: (a) work stress (b), grief, (c) anger, (d) legacy, (e) vulnerability, and (f) tension. These different themes can run in a cyclical pattern, but Carin also experiences many of them in a single moment, and some

days none of them. Throughout the interviews, Carin spoke about a pattern or cycle that she first noticed after Ben died. She specifically said that her work stress triggered her grief. From triangulating the interviews, documents, and observations, more elements emerged for this experience.

Work stress. Typical to normal life, Carin's work can be stressful because of its details, responsibilities, and tasks. However, unique to her working for a foundation created in response to her son's death, her work stress can also trigger her grief:

There is a cyclical pattern for me when things get very stressful at work. I recognize it now, I didn't in the beginning. When things get really stressful with deadlines, I begin to think, "I would not be doing this if my son was not dead." I don't want to be doing any of this. I hate this. Then you come out of it a couple days later and I think, "I better get back to work and do my thing." (C. Towne, personal communication, December 2, 2013)

When I bump up against something that I don't want to be doing but has to be done for the good of our organization, I get really frustrated and pissy because I don't want to be doing this thing. Then we said many, many times – we keep coming back to – what else would we do? If we went and took a job somewhere else doing something completely out of the pediatric cancer realm, we would still be thinking about Ben. We live in that tension all the time. (C. Towne, personal communication, December 17, 2013)

When I experience high levels of stress because of work, it automatically triggers grief for me because then I go down the path of "I wouldn't be doing this if my son was here. If Ben hadn't died, I would be doing the work I was doing."

Professional stress oftentimes triggers my grief. I then go down this dark hole of hating what I'm doing. (C. Towne, personal communication, December 17, 2013)

Grief. Once her stress triggers her grief, she is acutely aware that if Ben were still alive, she would not be working for Ben Towne Foundation at all. It would not exist:

We still come home [after the Benefit]. It doesn't change anything for us. That was probably an overly harsh reality. We came home that night – everyone goes home to their kids. We go back to the same life. It still sucks. Ben is still gone. Nothing changes. (C. Towne, personal communication, December 2, 2013)

What everyone wants is for what we're doing to give meaning to his death and his life. Even if we do cure childhood cancer in our lifetime, and I think we will, it still doesn't change our life. It doesn't change our grief; it doesn't change how much we miss him or long for him every day. But it has given us a way to move forward, it has given us something to do. And that does not negate his suffering or his death. (C. Towne, personal communication, December 2, 2013)

This leads her to the harsh reality that even while Ben Towne Foundation and the Ben Towne Center for Childhood Cancer Research work to find cures for childhood cancer, this research cannot change her life: Ben is still gone, and no amount of foundation work will bring him back.

Anger. This awareness and grief episode triggers her anger, and she feels hopeless and resentful of Ben Towne Foundation and its mission. Out of the anger comes a strong and visceral ache for her son:

It was definitely more to do with Ben. It still is. People want to put accolades on us, but I don't feel we are deserving, for multiple reasons. I'm not doing this to be

a saint or out of the goodness of my heart. We went into the world of cancer with our son, and then he left us there. We are not trying to save the world from suffering. We're angry. You can't see what we saw and have no response to that.

We didn't know what else to do with how hurt or devastated we were. (C. Towne, personal communication, December 2, 2013).

This is a low and dark experience for Carin, who said, "I don't really care because at the end of the day it doesn't change my life" (C. Towne, personal communication, December 2, 2013). "At the end of the day, I'm selfish. I don't care if this changes the circumstances for one hundred million people, I want my own son" (C. Towne, personal communication, December 17, 2013).

Legacy. Out of her continued love and connection to Ben, Carin desires to carry on his legacy. As she stated, "I wanted to give Ben a legacy. I wanted his name to be associated with something great that he didn't get to do on his own time" (C. Towne, personal communication, December 2, 2013).

The foundation gave me way to continue to talk about my son. People talk about their kids all the time. I want to talk about both of my kids. For me it was a tangible and appropriate way for me to just keep talking about him. It kept him from fading into the background of people's minds. (C. Towne, personal communication, December 2, 2013)

I don't feel like it has made Ben's death meaningful or made his suffering redeemed in some way. It's been our response to his death. We are going to do something about it. I don't believe there was a purpose in Ben's death. Are we making our purpose? I guess in some way we are. Yes, in one hand it's

meaningful. It's meaningful that we could do something in his memory. That people know who he is, obviously we care that people know him. (C. Towne, personal communication, January 21, 2014)

Ben Towne Foundation keeps Ben present in the ordinary everydayness of life. It is at this point where Carin appreciates Ben Towne Foundation and what it allows her to do in memory of Ben.

Vulnerability. Thousands of people followed the Caring Bridge blog that Carin wrote during Ben's time in treatment. Also, because of her husband's job as a pastor of a local church, as well as her immediate family's prominent Seattle presence, hundreds of people felt as though they were a part of this journey. Carin's openness and sensitivity plus the public nature of Ben Towne Foundation and her story has made her vulnerable:

I think we had to ponder the question, what do we do with the amount of people that were involved with us over the last two years? I think we wondered about that because there was such a community following of Ben's story. We wondered about if there was a direction we should point them in? People want to do something after someone dies because it makes them feel better. (C. Towne, personal communication, December 2, 2013)

Because of what I'm doing, it opens you up and makes you vulnerable to what people say. By putting yourself out there, it's an invitation for people to speak to your experience. That can also trigger the anger parts of grief. (C. Towne, personal communication, December 17, 2013)

Carin and Jeff knew that if these same hundreds of people also wanted to respond to Ben's illness and death, they could make a significant difference. At the same time, well-

meaning people also caused pain. People frequently spoke hurtful things to Carin. For example, “Isn’t it great how God orchestrated this whole thing?” (C. Towne, personal communication, December 17, 2013).

Tension. It is a complex situation: others being involved with Ben Towne Foundation plus the success of the research for treating pediatric cancer actually bring Carin mixed emotions. She has put much work into making Ben Towne Foundation a success and she is satisfied and grateful that people show up to the events and give generously. At the same time, she feels tension in those moments because it does not change the reality of Ben’s death. The level of excitement about the events at Ben Towne Foundation is sometimes difficult to balance emotionally.

At the Annual Benefit I attended, I thought about this tension during the cocktail hour. It was strange to realize that though music was playing and people were laughing and enjoying a cocktail, the reality of why we were there loomed as a somber and serious reality. Ironically, for many there, it was a fun night out and a time to enjoy seeing friends. During the program it was also exciting to hear about the success of the research and treatment that Ben Towne Center for Childhood Cancer Research has known (Observations, September 27, 2014).

In an interview, Carin reflected on the experience of the Annual Benefit:

At the benefit it is this amazing feeling of excitement and thankfulness that people actually came and showed up. At the same time, when you start seeing people having a great time, you’re like. “Why is everybody so happy? Everybody is having a great time and it’s because my son is dead.” It’s a very surreal experience. (C. Towne, personal communication, December 2, 2013)

In July 2013, Carin wrote the following on her blog after it was announced that the first patient who was treated with T cell therapy had a positive response and was in remission:

These past few days our hearts have been filled with so much emotion. How we longed to hear the words “no cancer” in relation to Ben. How we hoped, begged, prayed, pleaded and cried. If I go too far down that path of remembrance, I will not return for some time. So I pause. I honor that sorrow and then say thank you – to all of you – for the vast ways in which you have come alongside the Ben Towne Foundation. It is overwhelming to think about how you all have invested your time, talents and finances to get us to this place. (C. Towne, Ben’s blog, July 2013)

A second observation that revealed Carin’s tension occurred at the tour of The Ben Towne Center for Childhood Cancer. At the tour’s end, Carin shared a story about Ben, expressing that she had recently gone to her second-born son Ryan’s kindergarten holiday assembly. When the third graders came onto the stage, a wave of grief hit Carin: she was staring at what should have been Ben’s third grade class.

I had a moment of, “Oh my goodness, those would be my son’s peers, those would be his buddies.” They looked so big, they were so tall, they didn’t look like three year olds, they didn’t look like kids anymore. And I had that moment watching them where I couldn’t envision what Ben would look like as a third grader because he’s been gone for so long. But what I can envision when I come here, when I heard Mike [Dr. Jensen] speak, is a day when there are no longer families like ours, when there’s a day when families don’t have to make horrible

choices for their kids when they get a pediatric cancer diagnosis. (Observation, April 3, 2014)

As she was finishing the tour, Carin said, “We appreciate your generosity and your time today, and I hope you are going onto something much more uplifting or maybe comedic...” (Observation, April 3, 2014). When she said it, at first I was confused because the tour was exciting and hopeful. The success of the T cell therapy was uplifting, but Dr. Jensen’s confidence in his vision for curing all childhood cancers was downright contagious. So when Carin said she hoped we were going onto something more uplifting, it revealed more about her experience and reality of her life – more than it encapsulated my personal experience of the tour. For Carin, The Ben Towne Center for Childhood Cancer is about Ben and the reality that no matter the success and advancements of the research, it does not change his story: he is not coming home.

Question 4

The fourth question asked was, “What is the iterative relationship between grief and charitable work, and how did the primary participant experience this relationship in regards to meaning making and identity formation?” As stated earlier, data showed that Ben Towne Foundation gave Carin a way to proceed, a reason to get out of bed in the morning. Carin completed a Masters in Acting program not in Business Administration, so founding and working at the foundation presented her a major learning curve. At times, even now, Carin feels like she may not be the right person to work for Ben Towne Foundation:

The foundation and Ben do feel separate. The times when they don't feel separate for me are obviously if I'm speaking about him... When things got really stressful with deadlines, and I got worked up. It then spun off into "I wouldn't be doing this at my son was not dead. I don't want to be doing any of this. I hate this."

That's not really a normal reaction to a stressful situation at work. (C. Towne, personal communication, December 2, 2013)

This [Ben Towne Foundation] is the only way to respond right now... with the caveat that it may not be the only way to respond 10 years from now. I don't know. We've said that we were the right people to start this. There may be a time when we are not the right people to lead it anymore. That will have to be ok at a certain point. I personally don't think so. I think Jeff is the right person. I'm not sure I'm the right person. (C. Towne, personal communication, December 2, 2013)

Working for Ben Towne Foundation, to some degree, almost dictates that Carin holds onto her grief: "I can stay in the place of grief, it's appropriate to be experiencing what I'm experiencing in this venue" (C. Towne, personal communication, December 2, 2013).

In the early days of Ben Towne Foundation, it gave Carin a sense of purpose and direction to move forward in life. However, it seems that now as the years have gone on, Ben Towne Foundation ties Carin more closely to the traumatic story of Ben's treatment and death than would some other kind of work, such as her acting:

I live in that tension back and forth all the time. I'll be like, "I don't want to do this anymore. I want to walk away. I hate this. I don't want to be a part of this

anymore. I don't want to talk about cancer anymore." (C. Towne, personal communication, December 2, 2013).

Carin believes that her grief experience changes very slowly if at all. She says, "I don't think my grief this year is really any different than it was last year" (C. Towne, personal communication, January 21, 2014). Carin often speaks and shares her story at events and to people who are interested in Ben Towne Foundation, and every single time she tells his story she has to re-live Ben's suffering. She realizes that the start of Ben Towne Foundation was about Ben. Ben's story spearheaded its vision and mission. Five years later, however, it has grown in scope both scientific and personal, and more stories and families are involved. No longer simply advocating for Ben, it now advocates for many other children and families whose lives have been affected by pediatric cancer, and this effect will simply domino as years pass. For Ben Towne Foundation, this is positive for growth and recognition. However, for Carin it is personally more difficult. For example, I observed at the Annual Benefit Dinner that Ben's name was not mentioned until the end when Carin's gave her closing speech. It spoke to the fact that Ben Towne Foundation is growing beyond just Ben's story, as it should, if it is to fulfill its mission.

Other families shared their stories at the Annual Dinner. For example, the mom of the young girl whom the T cell therapy was successful at treating shared her gratitude for the research and the Ben Towne Foundation for saving her daughter's life. Still, Ben Towne Foundation has not changed Carin's story of loss; nothing can bring Ben back. She acknowledges and is passionate about fighting against cancer, but primarily because of Ben. She, too, is grateful for the success and changed lives of the T cell research. Still, the injustice of watching her own son suffer and die requires a response:

It was definitely more to do with Ben for me. It still is. It feels like we are advocating against his suffering. If I'm very blunt, it feels like – to cancer, "You can't fucking take my son's life and have us be quiet about it." You can't see what we saw and have no response to that. (C. Towne, personal communication, December 2, 2013)

But as Ben Towne Foundation grows beyond Ben's story, Carin is torn and the tension mounts. When asked, "Is it hard for you that Ben Towne Foundation is becoming bigger than Ben," Carin responded, "Yes. The answer is yes" (C. Towne, personal communication, December 2, 2013). She told a story of accepting an reward in the community for Ben Towne Foundation. The organization misrepresented Ben's story, and Carin responded as follows:

It was that exact tension for me; this [Ben Towne Foundation] is about Ben, but we are obviously expanding. We've gotten bigger. To have that recognition be so lacking in facts and incorrect information...it was utterly painful. It's [Ben Towne Foundation] been a definite transition to something else than when we first started. (C. Towne, personal communication, December 2, 2013)

Carin explained that as Ben Towne Foundation grows, its large September benefit event has required an event planner. Before the growth, Carin, Jeff, and Carin's sister organized and pulled it off. The September 2014 event will be the first year that Carin and her sister will not plan and organize the event. Carin reflected about this change: "I'm sensing that I'm going to feel slightly relieved to be one step removed from some of it. It will be relieving I think. It will be a mixture. It will be a push-pull for sure" (C. Towne, personal communication, December 2, 2013).

Being one step away from the stress regarding the event details has given Carin a sense of relief. It will not mean separation from Ben, but separation from aspects of the workload associated with Ben Towne Foundation. After the tour of The Ben Towne Center for Childhood Cancer Research, I asked Carin what she gets from working at Ben Towne Foundation, what makes it worth it? She replied:

It's a way to proceed. Something to do. A reason to get out of bed. And I suppose most importantly an occupation in which it is normal and expected for us to talk about our son (as opposed to working at Microsoft or Nordstrom or something). It doesn't take away the difficulty of it. But it would be hard wherever we were working. We have almost weekly discussions that are, "I don't want to do this anymore." Then, "But what would we do instead?" I guess thankfully neither one of us has really wanted to throw in the towel at the same time. Otherwise, we would probably close shop. (C. Towne, personal communication, April 1, 2013)

Throughout my interviews with Carin, the theme of "what else would we be doing" frequently came up. In the blog that Carin wrote on May 2, 2008, only eight months before Ben's death, she further explains her experience of doing something:

There is nothing extraordinary or superhuman about what Jeff and I are doing. People say things to us all the time like, "I don't know how you're doing this." Here is the enlightened answer: we have no choice. We are doing what any other parent in our same situation would do. The only thing we can choose is to get up each day. We get up (assuming we have actually been to bed). And we care for Ben to the best of our abilities. (C. Towne Ben's blog, May 2, 2008)

Apart from the foundation remains the firm relationship between Carin and Ben. It is separate from Ben Towne Foundation, yet it is this relationship that creates the messy and complex tension that Carin experiences. She stated, “It’s so messy and vague, yes he [Ben] is part of it, and at the same time it [the foundation] has nothing to do with my son” (C. Towne, personal communication, January 21, 2014).

The iterative relationship between Carin’s grief and Ben Towne Foundation is complex. Carin does not know what else she would do with her life apart from the Ben Towne Foundation: It enables her to grieve in an appropriate venue. However, working in a job that often requires her to go outside her natural talents and abilities creates frustration and stress. Also, as Ben Towne Foundation grows larger and more diverse, it is becoming less about Ben’s story alone. As research discovers treatment that can actually cure pediatric cancer, Carin’s tension mounts even more. The success of Ben Towne Foundation and The Ben Towne Center for Childhood Cancer does not change Carin’s traumatic experience endured through Ben’s diagnosis, treatment, and death. Still she wants to bring justice to Ben’s suffering, and by doing so, almost as a side point, she helps other families.

Summary

This chapter presented the findings for the study. I placed the findings as answers to the original four research questions. The first research question reads: What was the primary participant’s experience with grief and with starting Ben Towne Foundation? To answer it, I used a written narrative of the participant’s experience of the diagnosis, treatment, and death of her son Ben as well as her experience with grief and her

consequent establishment of Ben Towne Foundation. The second research question reads: What were the others' experience with grieving and being involved with charities/foundations? How did their experiences inform the primary participant's experience? I used three main themes to answer this question: (a) no purpose in death, (b) purpose in life, and (c) response to suffering. The third research question reads: How does forming a foundation to honor a deceased child influence the grieving process for a parent of the deceased child? I use six themes found in the data to answer this question: (a) work stress, (b) anger, (c) grief, (d) legacy, (e) vulnerability, and (f) tension. The fourth research question reads: What is the iterative relationship between grief and charitable work, and how did the primary participant experience this relationship especially regarding meaning making and identify formation? This answer emerged from the second coder's feedback as well as from the themes that emerged from the data.

Chapter 4

The purpose of Chapter Four is to present the reader with the interpretations of the study, as well as to present conclusions and recommendations. This chapter includes my interpretation of the findings plus the resulting future directions and implications for counseling. First, I integrate current research, sense making, and meaning making as each relates to grieving the loss of a child. Next, I discuss the idea of closure in parental grief and whether starting a foundation was helpful and/or healing in the grieving process for my participant. Next, Finally, I suggest future research recommendations and provide specific findings that may benefit mental health counseling. My conclusion follows all.

Meaning

To be able to discuss meaning, it is important to have a clear definition. According to Merriam-Webster's dictionary, meaning is defined as "something meant or intended" as well as "significant quality; implication of a hidden or special significance" (Merriam-Webster, n.d.). From the data, it was clear that the participants in this study all agreed that there was no meaning, or perhaps more accurately, no purpose, in the death of their children. However, all of them spoke about having meaning in life. The difference may seem slight but it is important to distinguish. For the participants in this study, there is no meaning in the death of their children; however, they have found meaning in life in the time that has passed since their child's death. They have found meaning despite the death of their child, not because of the death.

According the findings of this study, the ways in which the participants chose to respond to the death of their children, whether that was establishing a large foundation or

planting a garden, in no way gave meaning or purpose to the death of their children. For Carin, Ben Towne Foundation does not bring meaning or purpose to Ben's death. She does not believe that Ben had to die so that other children could live. However, for people on the outside, the tragedy and pain that the Townes have endured is difficult to bear. So in an attempt to soothe the existential inner crisis, it is convenient to assign Ben Towne Foundation as the meaning or purpose, somehow orchestrated by Ben's death. For Carin, this implication is not only incorrect, it is offensive. For other parents who have experienced the death of a child, this could be different. In the literature, parents have found meaning in the death of their children through religious or spiritual means (Keese, Currier, & Neimeyer, 2008).

Researchers including Neimeyer have explored sense making and benefit finding as it relates to the death of a child (Lichtenthal, Neimeyer, Currier, Roberts, & Jordan, 2013; Holland, Currier, & Neimeyer, 2006; Gillies & Neimeyer, 2006; Keese, Currier, & Neimeyer, 2008). In most of these studies, the researchers asked the parents the following two questions: 1) "Have there been any ways in which you have been able to make sense of the loss of your child?" and 2) "Despite the loss, have you been able to find any benefit from your experience of the loss?" (Lichtenthal et al. 2013).

Neimeyer's results are comparable to the responses I received when asking similar questions. According to the researchers' results, "Nearly half of the parents reported finding no sense (30%) or very little sense (17%)" (Keese, Currier, & Neimeyer, 2008, p. 1157). "The most common thematic response, given by 44.9% of the parents to the open-ended sense-making item, was that no sense could be made of the loss" (Lichtenthal et al. 2010, p. 799), and "...the most common theme that emerged in

the narrative was that they could not make sense of the death (53.1%; n=51)”

(Lichtenthal et al. 2013). According to these results, most parents could not and had not made sense of their child’s death. This research supports the findings from the current study.

Gillies & Neimeyer (2006) reported that people are driven by the need to find meaning in their lives, and that this sense of meaning is what can help people “face and transcend even the most horrific of experiences” (Gillies & Neimeyer, 2006, p. 31). Carin and the other mothers in the focus group had strong negative reactions even to the implication that there could be meaning in the death of their children. However, each have found personal meaning and purpose as they move forward in life. Research verifies that most parents who have lost a child say that they cannot make sense out of the experience (Gillies & Neimeyer, 2006; Keesee, Currier, & Neimeyer, 2008; Lichtenthal, Currier, Neimeyer, & Keesee, 2010). However, the researchers’ questions seem to imply that parents should be able to make sense or find benefit from the death of their child. It seems that the way the questions are worded could have been misinterpreted by the participants in the previous studies.

Victor Frankl (1959) wrote that, “In some way, suffering ceases to be suffering in the moment it finds a meaning, such as the meaning of a sacrifice” (p. 113). Frankl, however also goes on to say, “Let me make it perfectly clear that in no way is suffering necessary to find meaning. I only insist that meaning is possible even in spite of suffering” (p. 113). Frankl’s (1959) philosophy on suffering has been widely used in grief research (Gillies & Neimeyer, 2006; Schneider-Berti, & Berti, 2004; Barnes, 1994; Moller, 1986). In the foreword about Frankl’s theories Harold S. Kushner wrote,

“Suffering in and of itself is meaningless; we give our suffering meaning by the way in which we respond to it” (p. x). Kushner also wrote, “Most important, he [Frankl] realized that, no matter what happened, he retained the freedom to choose how to respond to his suffering” (p. 158).

According to Barrera, O’Connor, Mammone D’Agostino, Spencer, Nicholas, Jovcevska, Tallet, & Schneiderman (2009), theories on grief management have veered from focusing on a parent’s need for a process towards how to recover from the loss of a child. However, these researchers stated, “Contrary to earlier views, parents’ ability to maintain a continued bond with their deceased child and integrate this memory into a different socially-shared reality is now considered central to parental bereavement and adjustment” (Barrera et al. 2009). They examined the specific grief of parents who have lost children to cancer, noting its unique aspects such as anticipatory grief which they state “...is becoming increasingly common due to medical advances designed to prolong life, [and which] has important implication for parents and families bereaved from cancer” (Barrera et al., 2009). One of the findings in Barrera et al. (2009) study follows:

Fundraising for research and charity honoring their deceased child was a common activity. As one father (daughter, aged 14) said, “We have been really busy trying to organize the whole thing around the run for [the child]...focused on keeping [her] memory alive...There’s so much life still to live, you know, and she wouldn’t want me to be any other way, so I just keep going... [W]e want to make [her] life count for something.” (Barrera et al. 2009, p. 512)

Barrera et al. (2009) adds in the article, “Even though many parents felt that the experience had been devastating overall, they also admitted that it had provided myriad

opportunities for maturation, positive growth, and appreciation of new aspects of life” (Barrera, et al. 2009, p. 515). It seems that grieving may not be about trying to make sense of the death of the child; instead, parents seem to learn how to continue in life despite losing part of themselves. Life did not empty itself of purpose when the child died; what is important is life’s purpose and how a parent of a child who has died of cancer chooses to identify it. According to Woodgate (2006), parents who have experienced the death of a child have “...continued to live in a world without closure and, more importantly, [do] not want to experience closure in their transitioning” (p. 80).

Closure

As it relates to the current study, Ben Towne Foundation is a way that Carin has maintained a bond with Ben, as well as integrated his memory into a socially-shared reality as referenced by Barrera et al. (2009). Ben Towne Foundation has given Carin a way to keep Ben present in the everyday. According to Neimeyer and other meaning making research, this could be viewed as a way she has created meaning out of her loss (Gillies & Neimeyer, 2006; Keesee, Currier, & Neimeyer, 2008; Lichental, Currier, Neimeyer, & Keesee, 2010). However, as the findings of this study imply, Carin has not made sense or meaning out of Ben’s death, though life continues to move forward. Seeking closure was not something that came up in the data collected.

Woodgate (2006) found that parents, after experiencing the death of a child, live in a world without closure. Furthermore, not only is that the reality, but according to the current study it is preferred. Ben Towne Foundation may be beneficial to Carin’s grief in that it has given her a reason to get up each day. At the same time, it is also kept her close

to the traumatic story of Ben's death and may be viewed as something that could have a negative effect on Carin's grief process.

At the beginning of this study, I queried whether or not establishing a foundation or charity to honor a deceased child is helpful and healing in the grieving process. From the findings of this study, it appears that such a foundation can be helpful in the short time after the child's death. Ben Towne Foundation gave Carin a reason to move forward in life. However, it seems that after some time had passed, it may have prevented Carin from finding purpose beyond the experience of losing her child. If the specific way a parent chose to respond to their child's death continually keeps them in a state of re-living the experience of the death, that action could potentially be detrimental.

For Carin, Ben Towne Foundation keeps Ben's memory alive and honors him with a significant legacy. However, as she works for the success of Ben Towne Foundation, researchers are finding cures and treatments that would have possibly saved Ben's life. While Carin is optimistic about these results, it is a bittersweet feeling: Ben could have received T cell therapy if it had been developed a few years earlier. Her work is benefiting children; however, it does not change the reality of her experience of Ben's diagnosis, suffering, and death. The success of Ben Towne Foundation does not give meaning to Ben's death, but Carin's effort and work at Ben Towne Foundation is saving lives. However, this reality is difficult and creates tension for Carin who would do anything to turn back time to be with Ben.

Upon personal reflection, I realized that I chose my dissertation topic to understand the impact that forming a foundation would have on a parent's grief. My discomfort in learning about Carin's loss motivated me to try to find meaning in it

myself. The participants represented by the research described above, as well as the parents represented in my study all seem to agree that there is no meaning in the death of their children, and that seeking to make sense of this loss shows poor understanding of their experiences. As Carin stated in an interview, “People can’t leave what’s broken, broken” (C. Towne, personal communication, January 21, 2014). From this study, I found that for Carin there was not a way to find meaning in Ben’s death. However, by establishing Ben Towne Foundation, Carin has been able to continue to move forward in life, learning to live amidst the pain of her loss.

Lichtenthal, Currier, Neimeyer, & Keesee (2010) conducted research and found that parents who are unable to make sense of their child’s death are more likely to experience prolonged grief disorder (PGD). Though the researchers view PGD as a negative outcome to not making sense of death, from my study findings I think it may be the reality of Carin’s state. Living without a sense of closure is not because she has been unable to find sense or benefit from Ben’s death; it is because, in her lived experience, there is no sense or benefit to his death. However, Carin chose to respond – she chooses daily to work towards a cure for pediatric cancer. The reality is children are benefiting from his death, and other people perhaps are able to make sense of Ben’s death through the Foundation – yet for Carin, Ben Towne Foundation does neither. It links her to Ben in a way which gives her both direction and a purpose, yet also keeps her surrounded by the memories of suffering both her and Ben endured, and her continued grief at being separated from him.

Future Direction and Implications

Although parental grief is a widely researched topic, the impact of creating a foundation to honor a deceased child has garnered much less research. Further research on this topic is necessary, and it would benefit bereaved parents and families as well as mental health professionals. It would be beneficial to know more about the effects of establishing a foundation and how that impacts parental grief, as well as the grief of those connected to the family.

A potential future research direction may be whether parents react differently to the various causes of their children's death. For example, what differs for parents who lose children to pediatric cancer and parents who lose children to natural catastrophes? If parents feel their child has died unjustly or has suffered immensely, is their grief response more intense than the parents who lose their children through other means? Do the resulting foundations or charities come more typically from parents who respond to the unjust suffering of their children?

Furthermore, the topic of meaning as it relates to the death of a child warrants further development. One key consideration for future research regards the wording and sometimes erroneous assumptions of past literature about this topic. My study made it clear that the participants do not believe their child's death to have any meaning or purpose; however, most reported an individual sense of meaning in life. This crucial distinction opens the way to further research about meaning making and parental grief.

Specifically, my study gives mental health professionals one story of the experience of losing a child and creating a foundation. My findings could potentially help inform clients of the emotions and trauma that accompany the grief process. After losing

a child, a parent may want to respond to the injustice of the experience. Counselors should be aware and able to advise their clients of the complexity of establishing a foundation or charity to honor their child: not every family is financially equipped nor is every situation appropriate to create something significant and lasting. Parents may still respond and perhaps find some sense of justice as they donate or join other efforts already in place. Counselors can help parents understand that any foundation or charity involvement, whether their own or someone else's, will not necessarily give them a sense of meaning or purpose in the loss of their child; but, as documented in my research, it could potentially give them a purpose in life and a way to proceed.

Conclusion

In this study, I found that though establishing a foundation to carry on the legacy of a deceased child may give parents a way to proceed and a direction in life, it may also lock them into speaking over and over again the painful story of their child's death. For some parents this type of bond may be preferable, for being in a persistent state of grief actually could make them feel closer to their child. However, there often is potential for the foundation or charity to grow beyond their child's individual story, and as powerful and good as the growth may be, it can also create a new sense of loss.

My participant, whose story and experience supplied the majority of my dissertation findings, has mixed emotions surrounding the work she does for Ben Towne Foundation. It is possible that one day she may be ready to let go of Ben Towne Foundation and integrate more of her natural talents and passions into her future career. For now, however, Ben Towne Foundation helps her move forward and proceed with life.

In different ways, it is her connection to Ben; yet at the same time, it constantly reminds of her separation from Ben. Though she calls herself an ordinary parent responding as would any other parent in caring for her son and later leaving his legacy via the foundation in his name, the irreversible facts are that she experienced the trauma of watching her son be diagnosed with, treated for, and dying of cancer. She and her husband agreed to start Ben Towne Foundation to find a cure for pediatric cancer so no other family has to go through the pain and suffering their family has endured.

Nevertheless, dedicating her life to this mission requires her to re-live and re-tell the most traumatic experience of her life. A few times in our interviews I asked her, “Why are you doing this?” To answer this question is to dive deeply into her lived experience yet to discover no clear answers. I hope that my study shows a glimpse into one mother’s experience of starting a foundation to honor her deceased son plus the resulting complexities that both his death and also the foundation bring to her life. Discerning that meaning and following it in life will be a difficult journey, but it is a possible one.

The Well of Grief

*Those who will not slip beneath
the still surface on the well of grief
turning downward into its black water
to the place we cannot breathe
will never know the source from which we drink,
the secret water, cold and clear,
nor find in the darkness glimmering
the small round coins
thrown by those who wished for
something else.*

David Whyte

References

- Alam, R., Barrera, M., D'Agostino, N., Nicholas, D. B., & Schneiderman, G. (2012). Bereavement experiences of mothers and fathers over time after the death of a child due to cancer. *Death Studies*, 36(1), 1-22.
doi:10.1080/07481187.2011.553312
- American Cancer Society, Inc. (2013). *Cancer facts & figures 2013*. Retrieved from <http://www.cancer.org/research/cancerfactsfigures/cancerfactsfigures/cancer-facts-figures-2013>
- Barnes, R. C. (1994). Finding meaning in unavoidable suffering. *International Forum for Logotherapy*, 17(1), 20-26.
- Barrera, M., O'Connor, K., Mammone D'Agostino, N., Spencer, L., Nicholas, D., Jovcevska, V., Tallet, S., & Schneiderman, G. (2009). Early parental adjustment and bereavement after childhood cancer death. *Death Studies*, 33, 497-520. doi: 10.1080/07481180902961153
- Ben Towne Pediatric Cancer Research Foundation. (2014). [Website]. Retrieved from <http://bentownefoundation.org/>.
- Berzoff, J. (2006). Narratives of grief and their potential for transformation. *Palliative and Supportive Care*, 4, 121-127. doi: 10.10170S1478951506060172
- Berzoff, J. (2011). The transformative nature of grief and bereavement. *Clinical Social Work Journal*, 39(3), 262-269. doi:10.1007/s10615-011-0317-6
- Bowlby, J. (1980). *Attachment and loss: Vol. 3. loss: Sadness and depression*. London: Hogarth.

C Towne. (2007-2008). *Ben's blog*. Retrieved from <http://bentownefoundation.org/wp-content/uploads/2014/05/Bens-Journey.pdf>.

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed method approaches*. Thousand Oaks, CA, CA: Sage Publications.

Davis, C. G., Nolen-Hoeksema, S., & Larson, J. (1998). Making sense of loss and benefiting from the experience: Two construals of meaning. *Journal of Personality and Social Psychology*, 75(2), 561-574. doi:10.1037/0022-3514.75.2.561

Dickinson, E. (n.d.) I measure every grief I meet (561). In R. W. Franklin (Eds.), *The poems of Emily Dickinson*. Retrieved from <http://www.poets.org/poetsorg/poem/i-measure-every-grief-i-meet-561>

Frankl, V. (1959). *Man's search for meaning*. Boston, MA: Beacon Press.

Gillies, J., & Neimeyer, R. A. (2006). Loss, grief, and the search for significance: Toward a model of meaning reconstruction in bereavement. *Journal of Constructivist Psychology*, 19(1), 31-65. doi:10.1080/10720530500311182

Greeff, A.P., Vansteenwegen, A. & Herbiest, T. (2011). Indicators of family resilience after the death of a child. *Omega*, 63(4), 343-358. doi: 10.2190/OM.63.4.c

Grinyer, A. (2012). A bereavement group for parents whose son or daughter died from cancer: How shared experience can lessen isolation. *Mortality*, 17(4), 338-354. doi:10.1080/13576275.2012.730684

- Harper, M., O'Connor, R., Dickson, A., & O'Carroll, R. (2011). Mothers continuing bonds and ambivalence to personal mortality after the death of their child—An interpretative phenomenological analysis. *Psychology, Health & Medicine, 16*(2), 203-214. doi:10.1080/13548506.2010.532558
- Holland, J. M., Currier, J. M., & Neimeyer, R. A. (2006). Meaning reconstruction in the first two years of bereavement: The role of sense-making and benefit-finding. *Omega: Journal of Death And Dying, 53*(3), 175-191. doi:10.2190/FKM2-YJTY-F9VV-9XWY
- Holland, J.M. & Neimeyer, R.A. (2010). An examination of stage theory of grief among individuals bereaved by natural and violent causes: A meaning-oriented contribution. *Omega, 61*(2), 103-120. doi: 10.2190/OM.612.b
- Jakoby, N.R. (2012). Grief as a social emotion: theoretical perspectives. *Death studies, 36*, 679-711. doi: 10.1080/07481187.2011.584013
- Johnson, R.B. (1997). Examining the validity structure of qualitative research. *Education, 118* (2), 282-292.
- Keesee, N.J., Currier, J.M., & Neimeyer, R.A. (2008). Predicators of grief following the death of one's child: The contribution of finding meaning. *Journal of Clinical Psychology, 64*(10), 1145-1163. doi: 10.1002/jclp.20502
- Koffman, J., Higginson, I. J., Hall, S., Riley, J., McCrone, P., & Gomes, B. (2012). Bereaved relatives' views about participating in cancer research. *Palliative Medicine, 26*(4), 379-383. doi:10.1177/0269216311405091

Koin 6 News staff (2014). Paul Lee foundation set up to battle mental illness. Retrieved from [http://koin.com/2014/06/12/paul-lee-foundation-set-up-to-battle-mental-](http://koin.com/2014/06/12/paul-lee-foundation-set-up-to-battle-mental-illness/)

[illness/](http://koin.com/2014/06/12/paul-lee-foundation-set-up-to-battle-mental-illness/)

Kübler-Ross, E. (1969). *On death and dying*. New York, NY: Macmillan.

Kübler-Ross, E. (1983). *On children and death*. New York, NY: Macmillan.

Kushner, H. (2006). Forward. In Frankl, V. (1959). *Man's search for meaning*. Boston, MA: Beacon Press.

Lichtenthal, W. G., Currier, J. M., Neimeyer, R. A., & Keesee, N. J. (2010). Sense and significance: A mixed methods examination of meaning making after the loss of one's child. *Journal of Clinical Psychology*, 66(7), 791-812.

Lichtenthal, W.G., Neimeyer, R.A, Currier, J.M., Roberts, K., Jordan, N. (2013). Cause of death and the quest for meaning after the loss of a child. *Death Studies*, 37, 311-342. doi: 10.1080/07481187.2012.673533

McCarthy, M. C., Clarke, N. E., Ting, C., Conroy, R., Anderson, V. A., & Heath, J. A. (2010). Prevalence and predictors of parental grief and depression after the death of a child from cancer. *Journal of Palliative Medicine*, 13(11), 1321-1326. doi:10.1089/jpm.2010.0037

Merriam-Webster. (n.d). Meaning. Retrieved August 2, 2014, from <http://www.merriam-webster.com/dictionary/meaning>.

Moller, D. W. (1986). On the value of suffering in the shadow of death. *Loss, Grief & Care*, 1(1-2), 127-136.

National Center for Charitable Statistics. (2013). *Quick facts about nonprofits*. Retrieved from <http://nccs.urban.org/statistics/quickfacts.cfm>

National Cancer Institute. (2008). *National cancer institute fact sheet*. Retrieved from

<http://www.cancer.gov/cancertopics/factsheet/Sites-Types/childhood>.

Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA, CA: Sage Publications.

Riley, L. P., LaMontagne, L. L., Hepworth, J. T., & Murphy, B. A. (2007). Parental grief responses and personal growth following the death of a child. *Death Studies*, 31(4), 277-299. doi:10.1080/07481180601152591

Robinson, T. & Marwit, S.J. (2006). An investigation of the relationship of personality, coping, and grief intensity among bereaved mothers. *Death studies*, 30, 677-696. doi: 10.1080/07481180600776093

Rogers, C. H., Floyd, F. J., Seltzer, M., Greenberg, J., & Hong, J. (2008). Long-term effects of the death of a child on parents' adjustment in midlife. *Journal of Family Psychology*, 22(2), 203-211. doi:10.1037/0893-3200.22.2.203

Schneider-Berti, A., & Berti, G. A. (2004). Inner Transformation in Existential Crises: Renancer Groups for Bereaved Parents. *International Forum for Logotherapy*, 27(2), 65-76.

Shaw, R. (2010). QM3: Interpretative phenomenological analysis. In M. A. Forrester (Ed.), *Doing qualitative research in psychology: A practical guide* (pp. 177-201). Thousand Oaks, CA: SAGE Publications.

Vail III, K.E., Juhl, J., Arndt, J., Vess, M., Routledge, C., & Rutjens, B.T. (2012). When death is good for life: Considering the positive trajectories of terror management. *Personality and Social Psychology Review*, 16(4) 303-329. doi: 10.1177/1088868312440046

Vimeo (2012). Ben Towne Foundation Launch Celebration [Video file]. Retrieved from <https://vimeo.com/27341409>.

Ward, E., DeSantis, C., Robbins, A., Kohler, B., & Jemal, A. (2014). Childhood and adolescent cancer statistics, 2014. *A Cancer Journal for Clinicians*, 64, (2), 83-103. doi: 10.3322/caac.21219

Welch, J., Mannix, M. M., Boergers, J., Jelalian, E., Barbosa, F., Fujii-Rios, H., & Forman, E. N. (2012). Parental interest in a bereavement support visit when a child dies from cancer. *Omega: Journal of Death And Dying*, 65(4), 335-346. doi:10.2190/OM.65.4.f

Whyte, D. (2007). The well of grief. In *Where many rivers meet*. Retrieved from http://www.davidwhyte.com/english_wellofgrief.html

Woodgate, R.L. (2006). Living in a world without closure: Reality for parents who have experienced the death of a child. *Journal of Palliative Care*, 22(2), 75-128.

Yin, R.K. (2009). *Case study research: Design and methods* (4th ed.). Thousand Oaks, CA: SAGE Publications.

Appendix A

Open-Ended Interview Guide

The questions below make up a general open-ended interview guide that will be used over the course of 4-6 interviews with the participant. Due to the emergent style of the study, questions may be added or eliminated depending on the direction of each interview. Four interviews are described below, due to the emotional nature of the interviews they may be divided into six.

Demographic Information:

Name:

Age:

Education:

Occupation (current/past):

Interview 1: History of past experience

Goal of interview is to gain an understanding of the participant's experience with losing her son (leading up to his death and time following).

1. *Describe Ben to me.*
2. *Tell me about the time in the hospital.*
3. *How would you describe the time immediately following his death?*

Interview 2: History of Ben Towne Foundation

Goal of the interview is to gain an understanding of how the idea to start the Foundation began, and how that idea became a reality.

1. *Whose idea was it at first to start the Foundation?*
2. *Did you always want to be involved with cancer research?*
3. *What was your experience at the Foundation's outset?*

Interview 3: The Relationship between grief and the Foundation.

Goal of the interview is to gain an understanding of how the Foundation has impacted/affected Carin's lived experience with grief.

1. *How has the Foundation impacted your personal grief?*
2. *How has it impacted your family's grief?*
3. *Do you see it as a way to find meaning?*
4. *Have you found there to be unexpected benefits since creating the Foundation?*
5. *What would it feel like to not have the Foundation?*
6. *What have you gained from the Foundation?*
7. *How do you describe what the Foundation is to you?*

Interview 4: Future of the Ben Towne Foundation

Goal of the interview: To gain an understanding of how Carin views the long-term impact of the Foundation and how that affects her grief.

1. *Do you see yourself always working for the Foundation?*
2. *What happens when the researchers find a cure?*
3. *How would finding a cure affect your grief?*

Appendix B

Focus Group Interview Guide

1. Demographic information:

Name, age, name of child, what age they passed, how long ago?

2. Do you feel there was “purpose” or “meaning” behind the death of your child?

3. How have you sought to bring meaning? Or have you?

Appendix C

Observation/Field Notes

	People	Environment	Emotions	Interpersonal Interactions	Memories of Ben
Home					
Ben Towne Foundation Center					
Annual Banquet					

Appendix D

GRIEF AND CHARITY: AN EXPLORATION OF THE RELATIONSHIP BETWEEN
GRIEVING THE DEATH OF A CHILD AND CHARITABLE INVOLVEMENT**Consent Form for Primary Participant***Northwest University**Sarah E. Hanson, M.A.*

You are invited to participate in a research study conducted by Sarah E. Hanson, doctoral candidate for Northwest University. The purpose of this study is to learn about the relationship between grief and charity.

If you agree to participate in the study you will be:

- **Participating in 4 – 6 interviews**
- **Giving permission for the researcher to access & analyze personal documents**
- **Allowing the researcher to make and record observations of your family in your home, as well make and record observations at the Foundation and 2013 Benefit.**

(The purpose of the interviews will be to take an in depth look into the experience and life of you, the participant, as it pertains to the formation and ongoing involvement in the Ben Towne Foundation, as well as your own personal experience with the loss of your son).

There are minimal risks associated with participation. Some individuals may be uncomfortable answering personal questions. You may choose not to participate in this research study. The benefit of taking part in this study may be an increase in personal awareness.

Due to the public nature of the Ben Towne Foundation, as well as your personal story and involvement, confidentiality and anonymity is not possible. At anytime in the process it is your right to request the removal of any material from inclusion in the report of the study.

Participation in this study is voluntary. You may choose not to participate in this study at any time. You may refuse to answer any questions asked. It is your responsibility to keep this consent form for your records. By signing this consent form you are giving permission to conduct this study as outlined in this form.

The results from this study will be presented to the dissertation committee, and will be disseminated in written and oral form after completion. All data will be securely kept in a locked box, only accessed by the researcher.

If you have any questions about this study, contact ***Sarah E. Hanson (206) 683-9499***. If further questions, please contact my dissertation chair Jacqueline Gustafson, Ed.D. at (425) 889-5327.

Sarah E. Hanson, M.A.

Jacqueline Gustafson, Ed.D. - Chair

Name: _____ Date: _____

GRIEF AND CHARITY: AN EXPLORATION OF THE RELATIONSHIP BETWEEN
GRIEVING THE DEATH OF A CHILD AND CHARITABLE INVOLVEMENT

Consent Form for Focus Group Participants

Northwest University

Sarah E. Hanson, M.A.

You are invited to participate in a research study conducted by Sarah E. Hanson, doctoral candidate for Northwest University. The purpose of this study is to learn about the relationship between grief and charity.

If you agree to participate in the study you will be: **Participating in a focus group.**

There are minimal risks associated with participation. Some individuals may be uncomfortable answering personal questions. You may choose not to participate in this research study. The benefit of taking part in this study may be an increase in personal awareness.

Participation in this study is voluntary. You may choose not to participate in this study at any time. You may refuse to answer any questions asked. It is your responsibility to keep this consent form for your records. By signing this consent form you are giving permission to conduct this study as outlined in this form.

The results from this study will be presented to the dissertation committee, and will be disseminated in written and oral form after completion. All data will be securely kept in a locked box, only accessed by the researcher.

If you have any questions about this study, contact *Sarah E. Hanson (206) 683-9499*. If further questions, please contact my dissertation chair Jacqueline Gustafson, Ed.D at (425) 889-5327

Sarah E. Hanson, M.A.

Jacqueline Gustafson, Ed.D - Chair

Name: _____ Date: _____

GRIEF AND CHARITY: AN EXPLORATION OF THE RELATIONSHIP BETWEEN
GRIEVING THE DEATH OF A CHILD AND CHARITABLE INVOLVEMENT

Consent Form for General Participants

Northwest University

Sarah E. Hanson, M.A.

You are invited to participate in a research study conducted by Sarah E. Hanson, doctoral candidate for Northwest University. The purpose of this study is to learn about the relationship between grief and charity.

There are minimal risks associated with participation. Some individuals may be uncomfortable answering personal questions. You may choose not to participate in this research study. The benefit of taking part in this study may be an increase in personal awareness.

Participation in this study is voluntary. You may choose not to participate in this study at any time. You may refuse to answer any questions asked. It is your responsibility to keep this consent form for your records. By signing this consent form you are giving permission to conduct this study as outlined in this form.

The results from this study will be presented to the dissertation committee, and will be disseminated in written and oral form after completion. All data will be securely kept in a locked box, only accessed by the researcher.

If you have any questions about this study, contact *Sarah E. Hanson (206) 683-9499*. If further questions, please contact my dissertation chair Jacqueline Gustafson, Ed.D at (425) 889-5327

Sarah E. Hanson, M.A.

Jacqueline Gustafson, Ed.D - Chair

Name: _____ Date: _____