

**Children and Loss:
A Descriptive-Exploratory Study of
Bereaved Children's Experience of Loss
Following the Death of a Significant Adult**

by

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Abstract

This qualitative study describes the meaning of the experience of loss for four child participants following the death of a grandparent. Using both descriptive-exploratory methodology and human becoming theory as the framework, the findings are presented in three themes. Related to meaning of the experience of loss, the theme in the children's language is, sadness deepens with awareness of the permanence of death. Related to how relationships unfold following the loss of a grandparent the theme is, time spent doing things and with others provides memories. The final theme is related to hopes and desires the children had following the death of their grandparent, that theme is wishes to undo the past mingle with ongoing relating with one who has died. Practice implications and directions for further research are discussed in light of study findings.

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Dedication

Through doing this research I found myself reflecting on my relationships with my own grandparents and how memories of each of them weave in and out of my life. I dedicate this work in their memory. To the one who took the time to tie plastic oranges to a tree and told his surprised grandchildren that it was an “orange” tree. To the one who’s kindness and gentleness was respected by all. To the one who followed her convictions and beliefs and through her example taught me. To the one who died far too soon for any of us to know. I was a child blessed with a surrogate grandmother as well and want to thank her for her generosity in filling the gap at the times it was needed.

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Preface

My first experience in facilitating a support group for bereaved children has remained a powerful lesson influencing both my practice and my belief in children's abilities to share their experiences of the loss of someone significant. As only synchronicity could arrange, all of the children attending that group had a parent who had died by suicide. Each of the children did not know of the other's experience until the third session, when a five year old boy stood up and acted out what had happened to his father. This five year old was unable to put words to his experience; at the same time he desperately wanted to share it. He did it in the only way he knew how, by acting it out. I realized it was my role to help him share his message with the others, so despite my discomfort, I said "your dad shot himself?" "Yes" he said and promptly sat down as though a burden had been lifted. The electricity that ran through the rest of the circle of children was visible to the eye. These children, who had been slumped, reserved and spoken almost in whispers, lifted up in their bodies and said very clearly "so did mine." The mixture of amazement and relief for these children was undeniable. From that session forward, I had the immense privilege of seeing these children transform their experiences of loss. They were no longer alone, they were no longer ashamed, they were no longer burdened in the same way and most importantly, they were no longer silent. Based on the lessons from this group, I have conducted the following research study.

Chapter I

Introduction

The following study poses the question: “what is the meaning of the experience of loss for bereaved children following the death of a significant adult?” The theoretical framework used in this study is a human science theory by Parse (1992) called “human becoming”. The research was conducted in partial completion of a Master of Arts degree in Child and Youth Care.

I have worked as a counsellor in the field of palliative care for thirteen years supporting dying people and their families. “The focus of hospice palliative care is to relieve suffering and improve the quality of living and dying. This kind of care is appropriate for any patient and/or family living with a life - threatening illness” (Cairns, Thompson, Wainwright, 2003, p.5). Palliative care support by Hospice counsellors in the Victoria, British Columbia region includes continuing support with family up to one year after a death has occurred. Such support includes children who are experiencing or have experienced the death of someone important to them.

In doing course work for my Masters program; I began looking for research on children and loss. I was surprised by the minimal research available on the topic. I was disappointed to discover that existing research on children and loss did not reflect children’s experience in their own words. Thus, I chose to explore the meaning of bereaved children’s experience of loss following the death of a significant adult, due to the lack of first hand information from children about this topic in the palliative care field.

Rationale

The literature review that follows reveals that research on the subject of children's experience of the loss of a significant adult through death is scarce and mostly quantitative in approach. While quantitative methods offer one kind of knowledge generation, the contribution of bereaved children's own experiences is notably absent.

Wolfelt (1996) explains the importance of bereaved children having opportunities to talk about their experiences of loss following the death of someone significant to them:

When bereaved children internalize messages that encourage the repression, avoidance, denial or numbing of grief, they become powerless to help themselves heal. They may instead learn to act out their grief in destructive ways. Ultimately, not learning to mourn will result in not loving or living well. (p.6)

In my practice as a palliative care counsellor, I have supported adults seeking help to process a death they experienced in their childhood that they were unable to process at the time of death. These adults were often experiencing difficulties in maintaining current relationships and some were also diagnosed as being clinically depressed. If children are not supported in their experiences of the loss of a significant other, it appears to have the potential to shape how they may respond to later crises in their lives. It appears to have the potential to influence how they form and maintain relationships in their lives and possibly put them at risk for depression or behavior problems (Yagla Mack, 2001; Waters, Merrick, Treboux, Crowell & Albershiem, 2000; Worden, 1996). More will be said about this in the literature review chapter to follow.

As a practitioner, it also appears to me that practice built entirely upon adult perspectives cannot fully reflect nor attend to the experiences of children. Tammivaara & Enright (1986) articulate this concern as follows:

The result of this tendency on the part of adults to see the child's world in terms of their own prejudices and perspectives (dare we call it adult-centrism?) has been a systematic underestimation by researchers of the true abilities of children from infancy to adolescence, and a distorted portrayal of the world of childhood by adults in general. (p.227)

Contributions of the research

This qualitative study is intended to make several contributions. The first is to facilitate the opportunity for bereaved children to contribute to knowledge generation in the palliative care field. Research findings may provide new information to practitioners who work with bereaved children. It is also hoped that the information from this study may provide a starting place for further research that focuses on the experiences of bereaved children.

Theoretical framework

As stated earlier, the theoretical framework that shapes this research is Parse's theory of human becoming (1992). The theory of human becoming is rooted in the human sciences. According to van Manen (1998), "the distinction of 'Human Science' versus 'Natural Science' is often attributed to Wilhelm Dilthey (p.3) Phenomenologist and educator van Manen (1998), goes on to say:

... natural science studies "objects of nature," "things," "natural events," and "the way that objects behave." Human science, in contrast, studies "persons",

or “beings that have “consciousness” and that “act purposefully” in and on the world by creating objects of “meaning” that are “expressions” of how human beings exist in the world. (p.3-4)

Parse (1998), adds that Dilthey proposed “developing the human sciences to enhance the understanding of experiences as humanly lived. Dilthey believes that the human sciences should illuminate meanings, values, and relationships” (p.9).

Human becoming theory

Human becoming theory was developed by Rosemarie Rizzo Parse in 1981 and was first called Man-living-health. In 1992 she changed the name to human becoming reflecting the change that the dictionary had made to the meaning of the word man which was now gender specific. Parse states, “The words human becoming form a construct reflecting a conceptual bond that points to human quality of life and health as ongoing mutual participation with the universe” (1998, p.31). In this theory quality of life is “the incarnation of lived experiences in the indivisible human’s view on living moment to moment (becoming) as the changing patterns of shifting perspectives weave the fabric of life through the human-universe process” (Parse, 1998, p.31). This means that quality of life for each person is a unique perspective that consists of each individual’s experiences as they are continually being shaped by past, present and anticipated future events all at once.

Human becoming theory situates itself in the simultaneity paradigm. The simultaneity paradigm views “human wholeness [as] a patterned configuration, not the sum of particulate attributes. There is no body-mind-spirit triad but rather a human being recognized through patterns in mutual process with the universe” (Parse, 1992, p.35). In

the theory Parse refers to humans as unitary beings, reflecting that they are at one with the universe. In contrast, the totality paradigm views human wholeness as made up of separate parts such as physical, psychological, and spiritual.

Areas of previous knowledge which Parse drew from in creating human becoming theory are Roger's (1970) theory of nursing and existential phenomenology. It is through these two existing areas of knowledge that Parse created the assumptions for human becoming. Before relaying the assumptions I first want to explain that Parse writes concepts of the theory using the "ing" gerund "to make explicit the process orientation of the theory. For example, value has a more static meaning than valuing" (Parse, 1992, p.37).

Assumptions of the theory

Initially, Parse had nine assumptions but in 1992 she synthesized those down to three:

- Human becoming is freely choosing personal meaning in situation in the intersubjective process of living value priorities.
- Human becoming is cocreating rhythmical patterns of relating in mutual process with the universe.
- Human becoming is cotranscending multidimensionally with emerging possibles. (Parse, 1998, p.29).

From the three assumptions Parse identifies three themes meaning, rhythmicity and transcendence. To explicate what Parse is addressing in the first assumption on meaning, one must understand that meaning in this context is not static but instead constantly changes for people as they experience living. Parse says, "Meaning refers to

the linguistic and imagined content of something and the interpretation that one gives to something” (1998, p.29).

To explicate the concept of rhythmicity in Parse’s second assumption; it is important to understand that rhythmicity in this context refers to patterns of relating that are paradoxical. Paradoxical does not mean they are opposites; instead the premise is that they are “dimensions of the same rhythm lived all-at-once” (Parse, 1998, p.30). For example, a rhythmical pattern is joy-sorrow. Joy and sorrow are not viewed as separate experiences in this instance; instead they are viewed as part of the same continuum or rhythmical pattern.

Finally, to explicate the meaning of transcendence held in the third assumption, consider that “Transcendence is reaching beyond with possibles – the hopes and dreams envisioned in multidimensional experiences” (Parse, 1998, p. 30). Multidimensional refers to the many levels of the universe in which humans are able to draw from, their past, present and future. Possibles refers to what people are able to imagine.

Principles of the theory

The three principles of human becoming theory are intricately shaped by the three previously mentioned assumptions. The principles will first be offered individually followed by an explanation of the principle.

Principle one

- Structuring meaning multidimensionally is cocreating reality through the language of valuing and imaging. (Parse, 1992, p. 37)

Meaning is the personal reality an individual places on experience. According to Parse, imaging, valuing and languaging are concepts used in structuring meaning

multidimensionally. Imaging refers to how reality is constructed through mutual reflective (explicit) - prereflective (tacit) processes. Valuing is “confirming-not confirming cherished beliefs in light of a personal worldview”(Parse, 1998 p.38). People make choices about experiences based on what it is they hold as important. Languageing is relaying what a person values to others. This is done both through the paradoxes of “speaking-being silent and moving-being still” (1998, p.39).

Principle two

- Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing, enabling-limiting while connecting-separating.(Parse, 1992, p. 37)

Parse provides an example of this principle which makes it easier to understand.

... a person may choose to live joy in the foreground with a dying loved one, while the inevitable sorrow is all-at-once present in the background. In this situation, the person with the dying loved one reveals-conceals, is enabled-limited and connects-separates all at once. (Parse, 1998, p.43)

Again, this principle contains three concepts, revealing-concealing, enabling-limiting and connecting-separating. In any given moment a person both reveals part of him or herself and at the same time conceals part of him or herself. “There is always more to a person than what the other experiences in the immediate situation” (Parse, 1998, p. 44). With enabling-limiting, whenever a person chooses one direction that immediately limits possibilities in other directions. With the rhythmical pattern of connecting-separating, as one moves towards another (as defined by people, ideas, objects and situations) one automatically separates from something else. According to Parse, “The rhythmical

patterns of relating, revealing-concealing, enabling-limiting, and connecting-separating, are seen in everyday life experiences as identifiable manifestations of human becoming” (1998, p. 45).

Principle three

- Cotranscending with the possibles is powering unique ways of originating in the process of transforming. (Parse, 1992, p.38)

“This principle specifies that human becoming is moving beyond with intended hopes and dreams while pushing-resisting in creating new ways of viewing the familiar and unfamiliar” (Parse, 1992, p.38). The principle consists of three concepts, powering, originating and transforming. Powering is the rhythm of pushing-resisting. It is “an energizing force which sparks moving beyond the moment” (Parse, 1992, p. 38).

Originating is a way of establishing personal uniqueness. It involves the rhythms of conforming-not conforming and certainty-uncertainty. Conforming-not conforming arises “as individuals seek to be like others, yet, all-at-once, not to be like others” (Parse, 1998, p.49). Certainty-uncertainty reflects experiences of making choices while not knowing the outcomes. The final concept, transforming, refers to ways humans experience change. “New experiences connect with the meaning moments of the now as the changing view of what is gives new meaning to the situation” (Parse, 1992, p.39). Transforming involves the rhythm of the familiar-unfamiliar, this is a process of connecting what is already known about self or others with what is not-yet known as new experiences arise.

Now that the theoretical framework for this study has been introduced, I will go on to explain the rationale for using this theory. The rationale will be presented in two ways, through the theory’s connection to children and palliative care practice.

Human becoming theory and children

Parse's human science theory is rooted in the belief that people participate with the universe in the cocreation of their quality of life and health. Parse's theory encompasses all humans, she does not make a distinction between adults and children, and therefore her theory applies equally to research involving child participants.

Baumann & Carroll (2001) provide insight on how human becoming theory is appropriate in practice with children. Although the writers are referring to practice it is easily transferable to the use of theory itself. They state that human becoming theory:

...complements societal responsibilities by positing that children themselves are the experts on their quality of life. Children, like adults, live at multidimensional realms of the universe, and they cocreate their realities with families, communities, and other groups. Other adults and other children participate in shaping quality of life as children connect and separate with their families, schools, and communities. Children express their realities and intentions through words, artistic expressions, movements, and play, and although there may be shared concerns at various times in the journey of childhood, there is always a unique experience to understand. (p.121)

Human becoming theory and palliative care

Human becoming theory and palliative care share parallel philosophical concepts. Hutchings (2002) identifies four key parallels in practice, whole person care, the presence of paradox in human experience, primacy of the person, and presence or "being with" (p.411). In Human becoming theory, whole person care refers to paying attention to the multidimensions of a person when caring for them. The concept of whole

person care is foundational to palliative care. It has long been recognized in palliative practice that in order to provide care, one must consider the whole being rather than simply focusing on the illness itself.

I have long been aware of the paradoxical nature of caring for the dying and bereaved. For example, when supporting a bereaved child, I often hear that child speak of the experiences of joy-sorrow happening simultaneously when remembering someone who has died. When that child is in the midst of experiencing the death of someone they care about I hear them talk of wanting life to be the way it was before the illness appeared while recognizing at the same time that life has irretrievably been altered. Human becoming theory is the first theory I have found that has captured and provided language for the paradoxical experiences I have witnessed in working with people who are balancing living and dying, mourning and healing.

The third parallel addresses how both palliative care and human becoming theory hold quality of life as the goal of care. Both hold that quality of life can only be achieved when it is provided from the perspective of the person living the experience. The final parallel reflects the shared intent both human becoming theory and palliative care practice have of “being with” or “bearing witness” to another’s process. In my experience, many times in palliative care the most important action one can do is bear witness to a person’s experience of their illness, their dying and their grief for another. Parse reflects in her theory of human becoming the importance of being with people through what she calls “true presence.” “The nurse in true presence with person or family is not a guide or a beacon but rather an inspiring attentive presence that calls the other to shed light on the meaning moments of his or her life” (Parse, 1992, p. 40). It is the

interconnections between human becoming theory and palliative practice as well as how the theory embraces children as the experts of their own experience that provide the rationale for use of this theory as the framework for this study.

Phenomenon of interest

The phenomenon of interest in this study is the experience of loss for bereaved children following the death of a significant adult. A definition of loss as offered in Webster's Dictionary (1996) which is reflective of this study is "deprivation through death" (p.803). Rando (1984) provides further expansion to the definition.

Losses may be of two kinds: physical (tangible) or symbolic (psychosocial). Examples of a physical (tangible) loss include losing a desired possession or having a friend die; examples of a symbolic (psychosocial) loss include getting a divorce or losing status because of a job demotion. (p.16)

In writing to a friend whose son had died Freud said the following about loss:

We find a place for what we lose. Although we know that after such a loss the acute stage of mourning will subside, we also know that we shall remain inconsolable and will never find a substitute. No matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. (cited in Worden, 1991, p.19)

While any adult death was considered for this study, ultimately all the children who participated had experienced the death of a grandparent.

Research question

The question guiding this research is "What is the meaning of loss for bereaved children following the death of a significant adult?" As this question contains both

vocabulary and concepts that are likely too complex for the age of the participants interviewed in this study, the question posed to the children is simplified to match the language of the participants. A simplified question is one such as “What has it been like for you since (grandparent) died?” Other such simple language was used in posing all subsequent questions that flowed from how the child responded. (See Appendix D p. 109).

Purposes of the study

The purposes of the study were as follows:

- To discover and describe the meaning related to bereaved children’s experience of loss following the death of a significant adult.
- To offer an alternative understanding of bereaved children’s loss experiences following the death of a significant adult to the knowledge base already existing.
- To contribute to the body of knowledge regarding bereaved children in general and human becoming interpretation in particular.

Methodology

The methodology being used in this study is descriptive-exploratory. Descriptive-exploratory methodology has its roots in the qualitative descriptive methodology which was first used in social science research. “The nature of the research for the qualitative-descriptive method focuses on social connections, interrelationships, life events, and other matters concerned with the social sciences” (Parse, 2001, p.58). A number of human science researchers have used qualitative descriptive methodology including Parse. Parse endorses descriptive-exploratory methodology for use in research which uses

human becoming as its theoretical framework. She approves of the usage because “a discipline-specific theoretical perspective, such as theory of nursing, can be used as a conceptual framework to guide the research study” (Parse, 2001, p.57). There are two kinds of qualitative descriptive methods, the case study and the exploratory. Case study investigates a life event for one social unit such as a person. Exploratory investigates a life event for a group of people who share a particular phenomenon. As the phenomenon of concern in this study is the meaning of the experience of loss for bereaved children who have experienced the death of a significant adult, the phenomenon reflects a shared experience of loss between a group of people, in this study’s case, children. For these two reasons, the descriptive-exploratory methodology was chosen to conduct this study.

Conceptual framework

Parse’s (1992) theory of human becoming has provided the conceptual framework for this investigation. The three principles of the theory which were explained in detail earlier shape the three objectives of the study. I will now demonstrate the connections between the theoretical principles and the objectives of this study. I will then demonstrate the connection between the objective and the interview questions asked. It will be seen that each of the objectives of the study begins with the words “to describe” as that is congruent with descriptive-exploratory methodology.

To review, the first principle states, “Structuring meaning multidimensionally is cocreating reality through the languaging of valuing and imaging” (Parse, 1992 p. 37). This principle speaks to the way people make meaning of an experience through their own unique lens and that they share that meaning with others through the language they speak and the values they live. As the major concept in the first principle is meaning, the

first objective of the study, to describe the meaning related to bereaved children's experience of loss following the death of a significant adult, investigates meaning with the participants.

The second principle states, "Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing, enabling-limiting while connecting-separating" (Parse, 1992, p. 37). This principle speaks to how humans relate in paradoxical rhythms. In any given interaction one both reveals and conceals who they are. In relation with others, one is always making choices that enable certain opportunities while limiting other opportunities. Additionally, humans move towards and away from other persons, projects and situations all at once thus both connecting and separating at the same time. As the major concept in this principle reflects rhythmical patterns of relating, the second objective of this study is to describe how relationships unfold for bereaved children experiencing loss related to the death of a significant adult.

The third principle as stated by Parse (1992) is "Cotranscending with the possibles is powering unique ways of originating in the process of transforming" (p.38). This principle addresses the way that humans are able to shift their experiences in the midst of change. Humans go through a process of pushing and resisting experiences, which may ultimately lead to "shifting of views of the familiar as different light is shed on what is known," (Parse, 1992, p.39). The shifting of views is what Parse (1992) refers to as "transforming" (p. 39). As the major concept held in the third principle has to do with imagining the future, the third objective of the study is to describe children's changing perspectives on their desires, hopes and dreams following the death of a significant adult.

In order to maintain methodological congruence, the three objectives of the study then shape the questions that are asked while interviewing the participants. Again, to reflect the developmental level of the participants the questions are formed in simpler language. Once again the objectives of the study are offered, this time presented with the interview question which reflects that objective.

1. To describe the meaning related to bereaved children's experience of loss following the death of a significant adult.

- a. What has it been like for you since (grandparent) died?

This question is designed to begin to open up discussion that reflects the meaning of the experience of loss for the interview participants.

2. To describe how relationships (as defined by people, things or activities) unfold for bereaved children experiencing the loss of a significant adult through death.

- a. What is important to you about the people, things or activities you are speaking or drawing about?

This question is designed to begin discussion on what is important for the interview participants. The question provides opportunity to speak in more detail of the people, things or activities that they value.

3. To describe bereaved children's changing perspectives on their desires, hopes and dreams following the loss of a significant adult through death.

- a. How would you like things to be different?

This question is designed to begin conversation about what the participants' wishes and desires are within their experience of the loss of a significant adult.

Summary.

This introductory chapter lays out the foundation for the investigation of the meaning of the experience of loss for bereaved children following the death of a significant adult. The phenomenon of concern, loss, is identified as is the theoretical perspective used in this study. A description of the methodology is provided in addition to the research question, objectives and subsequent interview questions. The next chapter contains literature that pertains to the phenomenon of loss. This research is previewed with an eye to identification of gaps within the existing literature. In addition, the next chapter demonstrates how this study attempts to address some of those gaps.

Chapter II

Literature review

Introduction

The following literature review provides an overview of current research in a number of areas applicable to the research study. Bereavement literature that explores the impact of the death of a significant other will be reviewed. Following this, specific research related to children and their bereavement experiences is presented with a discussion of possible gaps. Finally, qualitative research with child participants and the implications and safeguards required for such research are described.

Search tools

The following search engines were used to conduct the literature review on children's experience of the loss of a significant adult; PsychInfo, Ebscohost, and Health Sciences. The keywords used to conduct the search included children and loss, children and grief, children and bereavement, children and mourning, children and death and qualitative research and children. Based on the limited research available in this topic area, the 1948-2004 time span was used to locate relevant literature.

Defining the topic

As already determined, the focus of this study is the experience of loss for bereaved children following the death of a significant adult. Research indicates that such a death has long standing implications for children's quality of life. A longitudinal study on attachment provides some insight into this. Attachment is the bond between infant and

caregiver that is formed by the caregiver responding to an infant's cries, smiles, laughter and eye contact. Through caregiver response to the infant's needs, a sense of trust and security about the universe develops within the infant. Attachment is the foundation for a human's emotional and social well being. The longitudinal study completed by Waters, Merrick, Treboux, Crowell and Albershiem (2000) indicated that forty-four percent of infants categorized as securely attached (i.e. they had a quality attachment) at 12 months of age had shifted to the insecurely attached category in early adulthood. Study findings indicated that this can be related to a negative life event such as the loss of a parent. Insecurely attached children are at greater risk of continuing to form poor attachments to others; low self esteem, or increased risk for depression.

In a study by Yagla Mack (2001), the researcher also found that children who experienced parental death had higher levels of depression in adulthood. These same children rated lower levels of self-confidence in adulthood. Yagla Mack (2001), used data from the National survey of families and households to examine the effects of childhood disruptions on adult well-being. The family disruptions she explored were parental divorce and parental death. From an original sample size of 13,017, 4,341 surveys were gleaned to provide the data for Yagla Mack's study. The 4,341 surveys met the criteria needed for Yagla Mack's research on family disruptions during childhood. The data was examined in terms of quality of parent-child relationship in adulthood, self-confidence, depression and childhood family structure. To control for variables, three different sets of comparisons were made to the data:

First, adults who experienced parental divorce as children were compared with those whose parents were married throughout their childhood. Second,

adults who experienced parental death were compared with those who grew up with continuously married parents. Finally, adults who experienced parental divorce were directly compared with those who experienced parental death. This analytic strategy was used to provide a more direct test of the differential effects of family disruptions than has been conducted in most prior research (Yagla Mack, 2001, p. 431).

The results of the parental death in childhood comparisons were informative. No significant difference in quality of adult parent-child relationships was found between those who grew up in intact families and those who had experienced the death of a parent in childhood. However, when looking at self-confidence it was found that those who had experienced the death of a parent had lower levels of self-confidence than those who had been raised in an intact family and those in divorced families. Finally, those children who had experienced the death of a parent in childhood had higher levels of depression than those in intact families or divorced families. This study again supports the importance of having better understanding of loss for children following the death of a significant adult as that loss can have longstanding impacts on further development.

Human becoming theoretical research on loss

Two phenomenological studies aimed at creating structures of the lived experience of grieving a personal loss (Cody, 1991) and the loss of an important other (Pilkington, 1993) reveal important information about the grieving process. Cody (1991) found:

The structure of grieving a personal loss uncovered in [his] study represents a way of being-becoming, a way of living value priorities ... The meaning of

the loss for each person [is] woven into the fabric of his or her own life. In this way, grieving a personal loss is a way that human beings live health. (p.67-68)

In this statement Cody points out that grief is a unique and individual experience of each human. Grief is experienced through the values and previous experiences of each individual. The structure of the lived experience of grieving as revealed in Cody's (1991) research is "intense struggling in the flux of change, while a shifting view fosters moving beyond the now, as different possibilities surface in dwelling with and apart from the absent presence and others in light of what is cherished"(p.64). What is helpful about Cody's research on grief is that the structure of grieving revealed does not pathologize grief; instead it reveals grief as a universal experience of humans that involves struggle, valuing, and transformation of past experience to present circumstances. All of this is done uniquely by each individual.

Similarly, research by Pilkington (1993) on grieving with five women who had lost a baby at birth revealed the structure of grieving as "an anguished suffering in devastating void amidst consoling movements away from and together with the lost one and others while confidently moving beyond personal doubts" (p.130). Again the structure revealed through Pilkington's research indicates grieving involves anguish over what is lost, valuing and relating to others while transforming experiences change meaning all at once.

Loss framework

Silverman (2000) provides a framework for loss experience for both adults and children. She describes the loss experience as a transition.

The transition does not have an ending date because the bereaved will continue to renegotiate the meaning of the loss for the rest of their lives. In this process, they develop new perspectives on their feelings and experiences and find a place for loss in their lives, which leads them to live differently in the world (p.32).

The transition is multidimensional according to Silverman (2000) and includes the bereaved developing a new sense of self and a new connection with the person who has died. When someone important in a person's life dies, not only is the person who died lost, but also lost are the bereaved person's roles in that particular relationship and the sense of self he or she had within that relationship. Notably important in regards to children is the awareness that "While a changing sense of self is normally a part of every child's life, for bereaved children this process is sometimes accelerated" (Silverman, 2000, p.33).

According to Silverman (2000), both adults and children find ways of constructing an ongoing relationship with the person who has died that is both comforting and sustaining (p.33). The ongoing relationship can take various forms and one form does not exclude another. Relationship continuation can involve identifying a place where the deceased person can be found, believing that the person who died continues to watch over the bereaved person, dreaming about and feeling the presence of the person who has died, having conversations with the person who has died and talking about that person with others. A final way identified is keeping things that belonged to the person who has died. Each of these thoughts, feelings or behaviors are ways in which adults and children alike keep alive their relationship with the person who has died (Silverman, 2000, p.34).

These studies led me to wonder how bereaved children create meaning of their loss experiences. A lack of qualitative research regarding the loss experience of children who have experienced the death of a significant adult led me to investigate a body of qualitative research exploring how adults experience and process the death of a parent.

Research on adult bereavement following the death of a parent

Recent qualitative studies have investigated the impact of a parent's death on adult children (Petersen & Ecchevaria Rafuls, 1998; Butchko Kerr, 1994; Dietrich, McWilliam, Ralyear, & Schweitzer, 1991; Galloway 1990). All studies revealed that the loss of a parent was significant, having implications in the lives of the adults. In Galloway's (1990) research, 20-39 year olds responded to an open-ended questionnaire. The young adults described the emotional impact of the loss of a parent as "being alone deep inside, sad or devastated" (p.901). They described the physical impact of grief as "fatigue, difficulty concentrating, uncertainty in decision making and loss of interest in a job" (p.901). The young adults also spoke of how the death of one parent impacted their relationship with the remaining parent as "assuming a parental role while the bereaved parent assumed the child role for either a short or prolonged period of time" (p.901-902). This study reveals that the death of a parent impacts many aspects of young adult's lives.

In research completed by Petersen & Ecchevaria Rafuls (1998), it is suggested that the impact of parental loss has a multigenerational impact. Using grounded theory methodology; six adults who lost a parent through death within the preceding two years were interviewed. "The emergent theme was of passing the scepter of roles and responsibilities previously held by the deceased parent to the next generation of the grieving adult child. Respondents assumed the responsibility of making things right for

the future generations of the family” (p.501). This research demonstrates that parental loss transforms the relational experiences of children and grandchildren.

Two studies by Butchko Kerr (1994) and Dietrich, McWilliam, Ralyea and Schweitzer (1999) investigated the meaning adult daughters attach to the death of a parent. Butchko Kerr’s (1994) study explored the connections between meaning adult daughters attach to a parent’s death and the length of their bereavement. Butcho Kerr (1994) states:

Those respondents who experienced a parent’s death positively, spiritually, or in terms of positive shifts in other family relationships, described a negative parent-daughter relationship, or reported any kind of change in lifestyle after a parent’s death, described the duration of their grief as lasting less than a year. On the other hand, those who experienced a parent’s death negatively, ambivalently, or in terms of negative shifts in other family relationships, described a positive parent-daughter relationship, or reported no changes in lifestyle after a parent’s death, described grief enduring as long as 3 years after the parent’s death. (p.356-357)

Dietrich, McWilliam, Ralyea, and Schweitzer (1999) conducted a phenomenological investigation describing five adult women’s experiences of losing their mothers. Seven themes emerging from the interview data included “recalling, holding on, saying goodbye, longings of the heart, shifting patterns of relationship, recreating the dialogue, and honouring our mothers/ourselves” (p.77). The researchers go on to elaborate:

The findings of this study reveal the relevance of relationship in women's experience of mother-loss. For the participants, the experience entailed recreating the relationship by recalling their mother's care and merging past and present – or their childhood and adulthood experiences . . . This recreation of the relationship facilitated the evolution of the grief process into a state of further personal individuation in an enduring connectedness that honoured both mother and self. (p.91)

The studies reviewed above tell us that the loss, grief or bereavement of a significant other has a profound impact in the lives of individuals. Further they strongly indicate that the meaning an adult attaches to such a loss influences one's ongoing quality of life. The next section addresses available research on the subject of bereaved children.

Research on children's understanding of the concept of death

There have been numerous research studies focusing on children's ability to understand the concept of death. Due to limited research on bereaved children's experiences of loss, this death concept research will be used as a beginning place to indicate what is known about children's loss experiences of a significant adult. In 1948 Nagy completed a classic study in the field of children's bereavement. This comprehensive study of 378 Hungarian children between the ages of three and ten years indicated that children proceed through three stages in their cognitive understanding of death 3-5 years, 6-8 years and 9-12 years. Nagy's findings indicated that children start to form an understanding of the concept of death in the 3-5 age grouping and that full adult understanding (i.e. that death is universal, inevitable and part of life) is reached by twelve years of age. The identification of developmental stages in understanding the death

concept advanced by Nagy continues to shape how people plan interventions in working with bereaved children although fifty years has lapsed since the study was conducted. Certainly, society has changed dramatically since the 1940's era of Nagy's study. The children of today are exposed to an advanced technological world and are likely to be more sophisticated in their development and thinking than the children represented in Nagy's study. Today's children are exposed to 25 to 27 violent acts an hour through children's programming. (Jenish & DeMont, 1992). Jenish & DeMont, (1992) state, "Other parents complain that TV violence is so routine that even death scenes barely make an impact on children" (p.2). Also, the children in Nagy's study were Hungarian and the impact of different cultures; values or beliefs on children's understanding of death were not addressed. As well, North American children of the twenty first century are likely to have differing developmental, cultural and societal experiences than the Hungarian children of Nagy's study.

More recent research by Hyslop-Christ (2000) builds on the findings from Nagy's classic study. Eighty-eight families with children ranging in age from 3-17 years participated in a research study that used both qualitative and quantitative methodologies. The families were recruited from a cancer treatment center in which one of the parents was undergoing treatment, had a terminal diagnosis, and had been given a life expectancy of three to six months. The families consented to participate in a psychoeducational intervention designed to facilitate the adjustment of the children to the terminal illness and subsequent death of their parent. The psychoeducational intervention directly involved the well parent and involved family connections with psychologists and social workers. Two psychologists met with the parents and children, administered a number of

tests and conducted a separate interview with each child and well parent. This procedure was repeated at 8 and 14 months after the death of the ill parent. In addition to these psychological tests, social workers were assigned to each family. The social workers conducted audiotaped interviews. Over “about 14 months [which] included six or more 60-90 minute interviews during the terminal stage of the illness and six or more after the death” (Hyslop-Christ, 2000, p. 35).

Like Nagy (1948), Hyslop-Christ categorizes the developmental understanding of death into age groupings. Hyslop-Christ identifies five developmental categories related to ages 3-5, 6-8, 9-11, 12-14 and 15-17. In the 3-5 aged category, the researchers found that these children “did not accept the finality of their parent’s death for several weeks or months. Emotionally, separations from the primary care taker aroused separation anxiety responses. Their social-ecological involvement was almost exclusively the family microsystem” (Hyslop-Christ, 2000, p.38). In the 6-8 aged categories, the researchers found children often:

... drawing wrong, often self-accusatory, inferences about the cause of the illness and death. Emotionally, they were more tolerant of separations, especially when prepared with explanations. The social-ecological development that affected their development also began to include the school”. (p. 38)

For the 9-11 aged category Hyslop-Christ (2000) found “They aggressively pursued detailed information about the illness and death that provided some sense of control and mastery. Emotionally, they could not tolerate grief, and escaped to the school, peer, and sports microsystems to avoid it” (p. 38-39). Twelve to fourteen years olds

evidenced “Emotionally, most characteristic were pubertal-early adolescent ambivalent emotional dependence-independence manifestations. They evidenced emotional withdrawal from parents. They avoided information about the illness and their own and other’s grief reactions” (Hyslop-Christ, 2000, p. 39). Finally, in the 15-17 years age category Hyslop-Christ discovered adolescents showed:

More sophisticated understanding of past-present-future implications of the parent’s illness. Their emotional dependence-independence was less ambivalent than that of the 12-14 year olds. They sought solace and support from peers more consistently. They had more adult-like grief. Their social-ecological horizon evinced greater understanding of the involvement of the larger community... (2000, p.39)

In another interesting study by Ellis and Stump (2000), adult perception of children’s ability to understand the concept of death was explored. The study used a demographic survey and included 352 people consisting of a group of parents (49) and a group of non-parents (303). The results of the survey indicated that parents believed children develop the concept of death (as measured by irreversibility) at an earlier age (Mean 5.5 years) than do non-parents (Mean 7.0 years). This study is helpful as it provides another updated perspective on Nagy’s findings and also reveals that different samples of adults have differing perceptions of what children are capable of understanding about death.

In a study completed by Orbach, Weiner, Har-even and Eshil (1994), the focus of investigation was whether or not an emotional context influences children’s understanding of death. The study measured children’s perceptions of death in relation to

interpersonal closeness to the deceased. The study included children in school grades one, three and five. One of the most important findings resulting from this study was the realization that the assessment of a child's understanding of death as conceived by the researchers, must take in to consideration that death is "a multifaceted concept and reflects the individual's self-perception and emotional state" (p.9). This statement reveals that cognitive development and emotional attachment both influence how a child processes another's death. In my practice, I am aware that cultural values and beliefs also impact how one understands and responds to death although this particular study did not look at those influences.

This study was important because it was the first to reflect the complexity involved in understanding death and the bereavement process. It provided data suggesting that children are capable of understanding this complexity. This study however, did not consider how a child's values and beliefs impact either his or her understanding as well as experience of the death of a significant adult. It would appear that there is a need for practitioners to know more about bereaved children's experiences of the loss of a significant adult.

Research on children's loss experiences

The literature discussed thus far considers children's understanding of death. Research on children's loss experiences is limited in the palliative care field today. Worden (1996) and Silverman and Worden (1992a and 1992b) used data from a sample of 125 nonclinical children between the ages of 6-17 years to publish three separate research studies. In the first study by Silverman and Worden (1992a) on children's reactions in the early months after the death of a parent, data from interviews that

occurred four months following the death were used. Semi-structured interviews with children and their remaining parent were conducted; in addition standardized measures such as the child behavior checklist, perceived competence scale for children and the locus of control scale were completed by both parents and children. The study identifies five areas reflecting the children's concerns, experiences and reactions four months following the death of one parent. The areas are, reactions to the death itself, affective experience, efforts to maintain a connection to the deceased parent, social networks and support systems and changes in family routines following the death (Silverman & Worden, 1992a, p.97). Seventeen percent of the children displayed problem behaviors in the first four months following the death while eighty-three percent coped well. Most children "were carrying on by going to school and by maintaining relationships with their friends and family members" (Silverman & Worden, 1992a, p. 102). The authors also found that "The parent's ability to assume a new role and to adapt to a single-parent household became an important factor in the children's overall adaptation to change" (Silverman & Worden, 1992a, p.102).

They state their most interesting find was the children's attempts to maintain a connection with the parent who had died. This was done in a number of ways, "through dreams, by talking to or frequently thinking about their deceased parents, by believing that their dead parents were watching them, by keeping things that had belonged to their dead parents, and by visiting their parents' graves. (Silverman & Worden, 1992a, p.100). The authors also found that most surviving parents were not paying attention to how their children were maintaining the relationship nor were they helping to foster this behavior (Silverman & Worden, 1992a, p.103).

The second study by Silverman and Worden (1992b) took a closer look at how the children maintained a relationship with their deceased parent. It used data from the first and second interviews with the children and remaining parent. These interviews occurred four months and one year following the death. Silverman & Worden (1992b) state,

... learning to remember and finding a way to maintain a connection to the deceased that is consistent with the child's cognitive development and family dynamics are aspects of an accommodation process that allows the child to go on living in the face of the loss (p.496).

Silverman & Worden (1992b) identify five categories which represent children's attempts to stay connected with the person who has died. They are, locating the deceased, experiencing the deceased, reaching out to the deceased, waking memories and finally linking objects (p.497). Seventy-four percent of the children located the parent who died as being in Heaven. This appeared to be true whether or not they had experienced any form of religious teaching. Eighty one percent of the children felt the parent who had died continued to watch over them and fifty seven percent of those children actually were frightened by this idea. Other ways the children experienced the deceased was through dreams and as "benevolent spirits" who communicated with the children through events such as the wind blowing a door open being interpreted as mother coming to visit (p.499). Children reached out to the deceased in this study by going to the cemetery and by speaking to their deceased parent. Waking memories were considered to be thoughts that the children had of their parent who had died. The study found that four months following the death, ninety percent of the children were "still thinking about their deceased parents at least several times a week" (p.500). Possessions of the parent were

also ways in which the children maintained their ongoing connection. The authors refer to these as linking objects (Silverman & Worden, 1992b, p.500). In summing up the findings in this particular study Silverman & Worden (1992b) state:

These findings suggest a shift in our understanding of the bereavement process. Bereavement should not be viewed as a psychological state that ends or from which one recovers... The emphasis should be on negotiating and renegotiating the meaning of the loss over time, rather than on letting go ... Thus bereavement should be understood as a cognitive, as well as an emotional, process that takes place in a social context of which the deceased is a part. (p.502)

Using the same 125 bereaved children and their remaining parents, Worden (1996) completed a two-year longitudinal study of children who had experienced the death of a parent. Worden (1996) found that there could be a late effect in the bereavement process. This late effect shows up 2 years following the death of a parent. Worden found an increase in the number of children who were assessed as being at risk for high levels of emotional/behavioral difficulties. As Worden says, "This finding makes a strong case for identification of children who will be at risk 1 and 2 years after the death so that early intervention can take place to preclude this late effect" (p.98). Risk factors include the child's level of self-esteem (low), suddenness of the death, as well as little or no preparation for the funeral. One key factor is how well or poorly the surviving parent is coping. If the surviving parent is dealing with health problems or depression, has a passive coping style or a number of family stressors and changes, then the risk for a late effect in the child's bereavement process increases. The findings of this study indicate

that children's experience of loss is a continuous process that calls for attention well beyond the early bereavement period so often referred to in the adult literature.

A study by Haine, Ayers, Sandler, Wolchick & Weyer (2003), explored locus of control and self-esteem as stress-moderators or stress-mediators in parentally bereaved children. "Locus of control and self-esteem are two dynamic self-system beliefs that children construct about themselves and their interactions with their social environment, which can serve either as a source of distress and or as an intrapersonal resource" (Haines et al, 2003, p. 621). The authors believe there are two different ways in which locus of control and self-esteem may influence the relationship between a negative life event (such as the death of a parent) and mental health problems. The two pathways are stress-moderation and stress-mediation:

In stress-moderation, the presence of the moderator reduces or increases the relations between negative events and mental health problems, thus acting as a stress-buffer or stress-exacerbator. In stress-mediation, negative events influence the mediator, which in turn impacts mental health, thus indicating that the mediator is a plausible mechanism through which stress may affect mental health. (Haines et al. 2003, p. 621-622)

Seventy-six children between 8-16 years of age and their surviving parent participated in the study. The time span following the death ranged from four to thirty four months. Two interviewers went to the family's home and one each interviewed the parent and child. The interview was structured and consisted of both parent and child responding to a number of standardized questionnaires, checklists or scales. For example, for the child items such as the perceived competence scale for children, revised children's

manifest anxiety scale and the children's depression inventory as well as a number of others were used. The parent completed portions of the child behavior checklist.

Quantitative data analysis revealed interesting results. First, no evidence was found for locus of control as a stress-mediator. Neither was there evidence of self-esteem and locus of control as stress-moderators for mental health problems. The data did reveal however that self-esteem significantly mediated both parent and child reports of internalizing problems. Haines et al. (2003) believe that "The results suggest that negative life events may reduce self-esteem, which in turn increases internalizing problems" (p. 633).

A comparative study completed by Worden, Davis and McCown (1999) explored the impact of parental and sibling loss on school aged children. Each child's social and emotional behavior was considered and was assessed by the parents using a Child Behavior Checklist. Findings indicated social and emotional behaviors were similar regardless of the relationship with the deceased. The findings of this study demonstrate the impact of loss experiences on children and clarify the need for practitioners to know more about children's loss experiences in order to effectively support them. An important way to know more about children's loss experiences is by asking the children themselves, something that has not yet been done.

Research on child participants in qualitative research

Ericksen and Henderson (1997) suggest the need for qualitative research with bereaved children. Ericksen and Henderson (1997) contend, "qualitative methodologies are particularly important in studying children's health care as they assist us in understanding the child's perspective"(p.1201). Fleitas (1998) echoes this belief stating,

“Qualitative research that reveals the meanings constructed by the children is imperative to the design of relevant systems of care that attend to the humanistic needs of this population”(p.3). Baumann (1997) states, “One goal of qualitative research with children is to do what Anne Frank, her father Otto Frank, and Mirjam Pressler have done. They have produced a document that represents the world as experienced by a child. In order to do this children must be viewed as valuable allies in research” (p.68).

Tammivaara and Enright (1986) offer insights into how to obtain good qualitative research results when interviewing children. These researchers suggest that adults must address the inherent power differential between the researcher and the child. Control of the interview should shift to the child. In other words, the research interviewer should not do all the initiating of dialogue within the interview and the interviewer should not attempt to control the child’s behavior before, during or after the interview. Knapp (1997) echoes this suggestion:

As I struggled to find ways to get Joshua to talk about what I wanted to know, interviewing him developed into a tacitly negotiated process. I would, for example, give him time to draw pictures during our talks or spend time looking with him at Waldo books that fascinated him in return for his serious attention to my questions. The trade off was 50/50; we spent about half our time together talking about things that interested me and about half our time talking about what interested Joshua ... Then I began to realize that these ‘off-task’ interactions were enabling me to build a real relationship with Joshua. He more than any other student, constantly begged me to interview him”.

(p.6)

Similarly, Garbarino and Stott (1989) emphasize that the interview process is a two way process between adult and child. The adult has responsibilities equally important to the child's in order for the interview to be successful.

The relative weight of adult evaluations and children's statements in the production of adult knowledge and policy virtually ensures that adult biases will overwhelm children's information when there is a contradiction. This is why it is so important for adults to be reflective about their biases and make special efforts to understand children's information and distortions from an empathic point of view". (p.183)

A final point to consider when doing qualitative research with children is to have materials for the child to use during the interview. "Young children generally find doing something with something and talking about that something to be easier, more comfortable, and more interesting than only talking about something that isn't physically present" (Tammivaara and Enright, 1986, p.232). Play materials are particularly helpful in carrying out qualitative interviews with bereaved children because the play material (such as drawing materials) helps create a natural distance between the child and the topic.

Summary.

This chapter reviews relevant literature reflecting the phenomenon of loss. It includes an exploration of theoretical understandings of loss as well as adult experiences of loss. Discussion includes research regarding children and loss. It is now clear that further qualitative research involving bereaved children is required in order for practitioners to gain needed insight for the purpose of supporting such children. The current research study provides a window into the experience of bereaved children in a

way that enables children's voices to be present in the field of bereavement research. The following chapter outlines the methodological procedures for the current study on bereaved children's experience of loss following the death of a grandparent.

Chapter III

Research Methodology

The qualitative research method used in this study is descriptive-exploratory. As previously stated, the descriptive-exploratory methodology is one form of qualitative descriptive research. Descriptive-exploratory methodology is “an investigation of the meaning of a life event for a group of people” (Parse, 2001 p.58). Three main assumptions underlie the descriptive-exploratory method:

1. Humans create social networks.
2. Humans can describe retrospective and prospective life events.
3. Patterns and themes surface through intense study of phenomena.

(Parse, 2001 p.57)

The study design of this research was modeled from a previous study completed by Baumann in 1994. There were two key reasons for following the template of Baumann’s study. First, the study successfully involved children in qualitative research methodology with no evident harm to the child research participants. Secondly, in another of Baumann’s studies on women and children who have no place of their own, a number of children freely discussed the loss of a significant other in their lives. Baumann states that although this was unintended, “Several participants drew funerals or graves. Participant 8 (boy, age 7) said, this is feeling uncomfortable; this is a grave; Grandma, I love you and you love me” (p.155). The data from Baumann’s (1994) study are indicative of the ease with which children describe their experiences when discussions are

conducted in the safe and non-intrusive manner called for in Parse's descriptive-exploratory methodology. The research process involved face-to-face individual interviews with four children that consisted of children having the choice of talking or drawing representative art of their loss experiences. The drawing time included time spent with the child asking him or her to describe the meaning of his or her drawing to the researcher. Baumann (1999) states,

Art as a path of inquiry is described here as one that avoids imposing a design or interpretation on art works, other than what is put into words by the artist. This view suggests that artistic skill or knowledge of theories of art are not necessary for the creation of art or the appreciation of the art of others as a path of knowledge. (p.107)

Although all four children in my study had the choice to draw or talk or do a combination of both, I found that only one child chose to draw and did so only after talking first. The discussion arising from her drawing revealed her drawing as a summary of the tape-recorded interview.

Sample

The study sample consisted of four children between 8-12 years of age who had experienced the loss of a significant adult through death. As it evolved, all of the children who agreed to participate in this study had experienced the death of a grandparent as the significant adult who had died. This similarity in significant adults who died makes the sample more congruent than I initially thought it would be. The rationale for children between the ages of 8-12 years of age is based on developmental information gained through the study by Hyslop-Christ (2000). It is recognized that a developmental

framework does not match the philosophical assumptions of human becoming theory which views human's as unitary beings who interact with the universe in unique patterns of becoming, however for the purposes of ethical review it is believed prudent to provide a developmental age grouping for the current study. As mentioned earlier, Hyslop-Christ's study involved eighty-eight families with children ranging in age from 3-17 years who had a parent who had a terminal diagnosis and a life expectancy of three to six months. Hyslop-Christ (2000) draws on earlier work by Jean Piaget regarding cognitive development and applies it specifically to children's experiences of having a dying parent and their grief processes:

Around seven or eight major new concrete operational thinking tools start to become available to the child. These include the ability to classify, to understand relations, to reverse, and gradually to conserve. The ability to classify means that with appropriate instruction the child can understand that not all tumors are cancer. Relations implies the ability to organize objects using some criterion, such as organizing sticks from largest to smallest, and inserting others into a pre-existing sequence. ... The ability to reverse is particularly significant. When discussing a child's erroneous conclusion (e.g., I caused Dad's cancer), the ability to reverse gradually allows the child to reexamine the steps that led to the original mistaken conclusion (Dad slipped on my spilled milk), and to introduce new evidence (he slipped months after he got cancer) and change the original conclusion. (p.29)

Hyslop-Christ provides more compelling evidence to how a sample group of 8-12 year olds was appropriate for this particular research study:

Three developmental characteristics were especially important in the ability of the children (9-11 years) to cope with the stress of the family tragedy: the emergence of logical thinking (concrete operational), more effective use of defenses against disquieting emotions, and an active engagement in the home, school, sports, and friend microsystems... as evidenced in their more meaningful participation in their own expanding world. (p.109)

Such developmental characteristics are important as they speak to the child's ability to understand information and to the likelihood that a support network is already in place for these children. If it is not already in place, based on the information from Hyslop-Christ (2000), children of this age grouping would be receptive to having one created should the need arise during or immediately following the interviewing process.

A sample size of five had initially been chosen based on rationale provided by Kvale (1996) who states, "Interview as many subjects as necessary to find out what you need to know" (p.101). He goes on further to explain:

A common critique of interview studies is that the findings are not generalizable because there are too few subjects. A paradoxical answer, from the history of psychology, is that if the aim of a study is to obtain general knowledge, then focus on a few intensive case studies. (p.102)

Finally, more specifically he says "In current interview studies, the number of interviews tend to be around 15+/- 10" (p.102). Finding five children to interview proved to be challenging so I compromised and settled on the interviews of the four participants I was able to acquire. Gall, Borg and Gall (1996) discuss estimating a desirable number of cases in this manner. They understand it as a trade-off between breadth and depth. "With

the same fixed resources and limited time, a researcher could study a specific set of experiences for a larger number of people (seeking breadth) or a more open range of experiences for a smaller number of people (seeking depth)” (p.236). The four interviews completed in this study did provide depth to describing the meaning of the experience of loss for bereaved children following the death of a grandparent.

I found it interesting to discover that others have also struggled to find participants in research involving dying or bereaved individuals. In Wright and Flemons (2002) article on qualitative research with terminally ill persons and their families, they describe the protectiveness that health care workers can project onto the families they are caring for and how at times this can make it difficult for researchers to gain access to this population for research purposes. “but when [Wright] contacted the administrators of a hospice organization, they refused to allow her to interview their patients out of fear that she would interfere with the patient’s dying process” (p.261). These two researchers also commented on what ultimately helped them obtain access to participants. The first step was finding an oncologist who was willing to support them in the search. Once the oncologist agreed, the researchers composed an explanatory letter that introduced Wright and the research study, and most importantly, was signed by the oncologist. The physician then gave the letters to people he felt were appropriate and Wright followed up with a phone call. When Wright asked the participants what had been the deciding factor in their agreeing to meet with her, all said “Without her association with their doctor and without the letter he had signed, they would not have opened their lives to her scrutiny” (2002, p.262). My own experience of finding it difficult to recruit families to participate in my research study led me to wonder if there was not a better way to initially make

contact with the families. I had also thought that an endorsement of some kind may have made it simpler and was interested to find that such ideas were being discussed and supported in the literature on qualitative research within palliative care.

A period of eighteen months following the death of the participant's significant other was required in this study. Although in clinical practice, early opportunities to discuss the death of a parent or other person that is close to the participant could be considered welcome, beneficial or cathartic by some for the purposes of this research study this time requirement was included to provide a form of linear distance from the child's loss experience and the one-year anniversary date that hopefully prevented the children from participating in this research study too soon. Further, the death of the child's grandparent occurred no more than three years prior to their participation in this study in an attempt to keep the sample congruent.

In addition, the children volunteering to participate in this study had experienced the loss of a grandparent who was cared for and treated through the Victoria Hospice program. The rationale for this is that the family had some professional support through the dying process and had not experienced a sudden death through accident, suicide or homicide. Families who have experienced a sudden death through the aforementioned circumstances were not included in this study due to the known long standing implications such a death can have for a family experiencing this kind of loss. It is important to note that although the children interviewed did at one time receive services from Victoria Hospice they were no longer using these services when they were invited to participate in the research. The decision to use Victoria Hospice as the sample source was also based on their program philosophy that encourages the inclusion of children in

both the dying and bereavement processes occurring within a family unit. This meant that the children likely had some previous opportunities to share their experiences of loss with another person, whether it be family member or professional.

Recruiting families

Letters of invitation were sent to families who were waitlisted for Victoria Hospice's parents and children's bereavement support groups, bereavement day camps or those who had individual counseling support who had children between the ages of 8-10 years of age and who had experienced the death of a significant adult between 18 months and three years previously (Appendix A, p.104). The letter informed families of the proposed research study and how their child could participate. In total 16 families met the initial sample requirements. From that group, three families responded expressing more information about the study. A follow up phone call was made to all other families who did not call in on their own in order to answer any questions the family had about the research and to determine whether they were interested in participating in the research (see Appendix F, p. 111). The researcher found a variety of responses from these families. Two adults felt that their children were currently doing well and were concerned that participating in the study might increase risk of the child becoming upset again. One adult explained that their child had experienced another loss following the death at Hospice and felt that the family was too vulnerable at this time to participate. Another family felt that their schedule was too full to be able to accommodate time to participate. Four families spoke with their children and the child him or herself said they did not wish to participate. Two families were unable to be contacted, as Victoria Hospice did not have the correct address and phone information for them. The researcher also found that

during these phone calls three families wanted to talk about specific concerns regarding one of their children and the researcher obliged providing information and support where it was appropriate. The remaining families the researcher was unable to reach.

For the three families who had expressed an interest in participating in the study, an individual face-to-face meeting was then scheduled with each family. This meeting served several purposes:

1. To provide further explanation of the research to those interested in volunteering to participate.
2. To obtain informed consent from the parents and children volunteering to participate.
3. To determine that the children were willing participants and address any concerns about possible coercion.
4. To introduce myself to the children in order to begin building rapport for the later planned interviews.

I met with two families in their homes and one family at Victoria Hospice as that family requested meeting there. I found these initial meetings to be important in establishing rapport with the children. I found that all of the children were confident in participating in the interview on the day of its occurrence after having first met me in the initial face-to-face meeting.

As stated earlier, one of the purposes of the initial face-to-face meeting was to discuss the study and obtain consent if appropriate. In this study, children were active participants in the consent process. I explained to the parent(s) and child beforehand in the face-to-face meeting together, the structure, intent, and future purposes for the

research information. It was explained to both the parent(s) and child that the child had the option to withdraw from the research at any point in the study. Both the parent(s) and the child signed a consent form (See Appendices B & C, p. 105-108). This process happened by having the parent(s) preview the adult consent form, ask any questions they had about the research and if agreeable, sign, along with the researcher. I reviewed the child's consent form with the child and invited the child to ask questions about the form and their participation in the study in general. Once the child determined he or she understood their role in the research study and the information the consent form contained, the child then signed the form along with the researcher. Both child and parent were given a signed copy of each consent form to keep. I also took a copy of each signed consent form for record keeping purposes.

While it is realized that assent from the child is what was required (rather than full consent which needs to be gained from the parent(s)) it was believed by this researcher, that having a consent form for the child was empowering for the child in the research process. Lepine & Smolla (2000) state, "it is preferable to obtain a child's assent positively and explicitly, as the mere absence of objection is not equivalent to valid assent" (p.55).

I also needed to be certain that the child wanted to participate in the study and was not being coerced by a parent. It is essential that "the researcher must make it clear that there will be no punishment for not participating if the child refuses" (Powell, 1994, p.446). This important information was in fact discussed with the parent(s) over the telephone when contact was made with the families following the letter of invitation. It was also reviewed in the face-to-face meeting with the family to insure that the child

knew that he or she could stop the research process at anytime without consequence. In the case of parental coercion, participation of the child in the research study would have been declined; however, it was not an issue in this particular circumstance.

During the initial meeting with the family, I also completed the demographics collection sheet (see Appendix E, p.110). The sheet provided important background information before the interviews were conducted. In particular, it was important to know of other losses the children had experienced (if any) in addition to the death of their grandparent. I was grateful to have had the knowledge of these other losses before the interview because the children did make reference to them during the interview itself. For example, two of the children had experienced multiple deaths the six months surrounding their grandfather's death. It was only natural that during the interview they would speak to those losses as well.

Data collection

Data was gathered through face-to-face audio taped interviews in which the children had the option of talking or using drawing as a tool for expression and exploration. Three of the four children chose to talk and the fourth child decided to talk and make a drawing following the conversation. The interviews took place in a play therapy room located in downtown Victoria. The child friendly environment of the playroom was deliberately chosen by the researcher as the location for the interviews. A child friendly environment was believed to be conducive to creating a safe environment for the children. It was also believed to be a more neutral location than doing the interviews within the child's own home. Within their own home, the child may not have felt as free to express him or herself due to the desire to protect either parents or other

siblings. Victoria Hospice was also felt to be too clinical a location, lacking a child friendly environment. Interviewing at Hospice also ran the risk of giving the interviewer covert power because the children were aware that I had contacted them through my association with that organization. As there are always inherent power issues to consider when adults are interviewing children, location of the interviews was one way to address some of the imbalances.

Using the playroom also made it convenient for parents as well as there was a comfortable and private room for them to wait in while their child's interview was taking place. The child also had the knowledge that their parent was immediately available to him or her should the need arise. It is interesting to note that from the child's perspective this did not appear to be an issue. One child expressed the desire that her mother "go shopping" while the interview was taking place and two other children were fine with their parent coming and going from the building during the interview time frame. One child's parents chose to wait in the garden adjacent to the building and the child gave agreement to this.

Each interview was approximately thirty minutes in length. The semi-structured interview consisted of three questions flowing from the objectives of the study. How the questions arose through the interview were not predetermined, rather they flowed naturally from what the children were sharing in conversation. The time to end the interview was determined by the child thus following the child's lead in the research process. Immediately following the interview, each child was invited to engage in a wind down activity for thirty minutes. The wind down activity was offered as one of several forms of follow up support to the child in recognition of the emotional content of the

phenomenon of study. Each child readily engaged in some kind of play activity ranging from creating a card game with me to complex strategy games using castles and an exploration of various musical instruments available in the playroom.

Upon completion of each interview and wind down activity, I reflected on the interview in a journal and noted my observations of what happened with each child in terms of both verbal and nonverbal communication during the interview process. I also noted the activities that occurred during the wind down period.

Rigor

The notion of validity in qualitative research is addressed through attention to rigor. According to Parse (2001), rigor of research occurs through “a scientifically sound design where the ontology, epistemology, and methodology are congruent” (p.59).

Congruence is demonstrated by the development of a research question that identifies a particular phenomenon, in this case children’s experience of loss following the death of a significant adult, as understood through a discipline-specific theory. The theory used in this research is the theory of human becoming. The objectives derive from the three principles of the theory and from the question itself. Additionally, the interview questions are shaped by the objectives. Finally, the data is analyzed through a process of analysis-synthesis and the findings are interpreted through the lens of human becoming theory.

Burns (1988) provides suggestions for qualitative researchers to follow in order to write a study that is rigorous. She describes five standards through which qualitative research can be evaluated. The first standard is descriptive vividness. “The description of the site, the subjects, the experience of collecting the data, and the thinking of the

researcher during the process needs to be presented so clearly that the reader has the sense of personally experiencing the event” (p.48).

The second standard is methodological congruence. According to Burns, there are four dimensions to methodological congruence, rigor in documentation, procedural rigor, ethical rigor and auditability:

Rigor in documentation requires the presentation, by the author, of all the elements of the study: phenomenon; purpose; research question; justification of the significance of the phenomenon; identification of assumptions; identification of metatheories; researcher credentials; the context; role of the researcher; ethical implications; sampling and subjects; data-gathering strategies; data analysis strategies; theoretical development; conclusions; implications and suggestions for further study and practice; and a literature review. (Burns, 1988, p.48)

Procedural rigor refers to the importance of the researcher indicating the “steps taken to ensure that data were accurately recorded and that the data obtained are representative of the data as a whole” (Burns, 1988, p.49). Ethical rigor requires the researcher to clarify the ethical implications of the study. It also acknowledges that informed consent is obtained and that confidentiality and the right to withdraw from the study are adhered to. Finally, the fourth dimension is auditability, which is the inclusion of a decision trail “the researcher must report all of the decisions involved in the transformation of data to the theoretical schema” (Ibid). The aim of the reporting is that it be so transparent that “a second researcher, using the original data and the decision trail, arrive[s] at conclusions similar to those of the original researcher” (Ibid).

The third standard that Burns (1988) purports is analytical preciseness. “analytical preciseness requires that the researcher make intense efforts to identify and to record the decision-making processes through which transformations were made. The processes by which the theoretical schema are cross-checked with data must also be reported in detail” (p.50). According to Burns (1988), the fourth standard for qualitative research is theoretical connectedness. This “requires that the theoretical schema developed from the study be clearly expressed, logically consistent, reflective of the data, and compatible with the knowledge base of [the discipline]” (p.50). However, it is also understood that, on occasion, data may also contradict existing data.

The final standard for qualitative research as proposed by Burns is heuristic relevance. This standard contains three dimensions. The first is intuitive recognition which means readers “immediately recognize the phenomenon being described by the researcher and its relationship to a theoretical perspective” (1988, p. 51). Burns’ second dimension is “relationship to an existing body of knowledge”. She states, “[The] theoretical perspective from which the phenomenon was approached must be reviewed by the researcher and compared to the findings of the study” (Burns, 1988, p.51). The final dimension is applicability. According to Burns (1988), the findings should “contribute to theory development within the discipline and guide future development of studies” (p.51). Burns’ guidelines were used as a road map in this study to address rigor in qualitative research.

Data analysis

The central purposes of data analysis within the descriptive- exploratory research method are to identify themes and to construct a description of the phenomenon. Parse

identified a specific way in which to handle data analysis in the descriptive -exploratory methodology. This process is referred to as analysis-synthesis. "Analysis-synthesis is a process of separating the themes according to the major elements in the objectives, examining these elements, and constructing a unified description of the phenomenon as lived by the subjects. The major themes are transformed to a higher level of discourse in the move from the subject's language to the language of the researcher" (1985, p.94).

In adherence to analysis-synthesis, dwelling with the data is required. I did this over a period of several months and in a number of ways. First, I transcribed the interviews verbatim (with the exception of changing participants' names). Following transcription, I listened to each individual's audio-taped interview while following along with the transcription three times. If the interview involved a drawing, I also looked at the drawing while listening to the audio-tape and following the transcription. While listening to the tape and viewing the transcription; I at times made pencil notes in the margins indicating where I thought the data reflected the three objectives (meaning, rhythmical patterns and cotranscendence, which reflects the participants' hopes and dreams). My next step was to create three separate documents that represented the three objectives of the research study. In each of these documents I placed all participants' statements that reflected that specific objective. I then had a document that reflected all participants' major ideas regarding a particular objective. The next step was to move to identifying major ideas common to all participants. Again I created three separate documents that reflected the three objectives but this time the information that went into the documents contained ideas regarding each objective that were common to all participants. From there I began to develop statements in the language of the participants that identified the

theme for each objective. Once I had the themes identified in the language of the participants, I then interpreted those statements into the language of human becoming theory. Guidance in doing the analysis-synthesis was sought through writings by researchers such as Parse (2001), Carson and Mitchell (1998), Baumann (1994) and Jonas (1992) who have used descriptive-exploratory methodology in conjunction with human becoming theory.

Ethical considerations

There is an important need to include children in research in order to provide insight and understanding into how children experience their world. Greater understanding enables practitioners and parents alike to support and attend to the needs or concerns of children in useful and rewarding ways. Research that involves children is viewed as beneficial to children in this research study as it provides children the opportunity to speak to important experiences in their lives within an environment that is respectful and with a format (drawing or talking) that suits their unique way of expression. It is important to consider that it may even be unethical to not include the voice of children in research. Lepine & Smolla (2000) state, "The concept of distributive justice dictates that the benefits and discomforts related to research must be distributed fairly, both individually and collectively. This means that there is a social obligation to conduct research with particular groups to avoid cutting them off from scientific advancement" (p.51). While it is important to include children in research, this also means that there are particular ethical issues that must be considered when conducting such research studies. In accordance with Burns (1988) requirements for methodological rigor which includes the need for ethical rigor, the following considerations were

addressed. Methodology, impact of the research on the participants, issues of power, and finally considerations of the researcher were explored. The following sections of this chapter give in-depth consideration to each of the issues and discuss ways to address them.

Ethical concerns about methodology

The research approach used in this study required bereaved children to be direct participants in the research process. Rosenblatt (1995) offers insight regarding bereavement interviews with adults, “I think bereaved people may gain enormously from talking with someone who takes their stories seriously and witnesses and acknowledges their pain” (p.144). As a practitioner working with bereaved children, it has been my experience that providing children the opportunity to tell their stories to someone who takes them seriously is enormously healing for them. Rowling (1999) found in doing her bereavement research with adults that “someone ‘doing research’ gave permission for people to talk about what is still a taboo topic and /or experience of powerlessness” (p.172). Rowling (1999) observed that although the interviews were emotional for the participants at times, no one refused to participate in further interviews. Both Rosenblatt (1995) and Rowling (1999) found that research participants described the research interview as therapeutic. Rosenblatt (1995) also states,

In research interviews focused on loss, the investigator typically asks a person to tell the story of the loss, and in that narrating there can be integration, crystallization, naming and healing that comes with the story form. I am not surprised when people tell me that a research interview benefited them therapeutically. (p.150)

Based on my clinical practice with bereaved children, I have found that children, who have the opportunity to talk of their loss experiences with someone who takes them seriously, gain insight into and understanding of those experiences for themselves. While it is recognized that practice context is different from research context, as the above previously cited research on adults dealing with a loss indicates, people find the experience of telling their story healing whether it is for therapeutic purposes or research purposes. My practice experience tells me that this is not different for children.

To address the possible changing needs of child and family participants, a protocol for the researcher to follow was laid out before the interviews were done (see Appendix D, p. 109) If a child was clearly distressed during an interview as observed by such behaviors as agitation, anxiety and disengagement in talking with the researcher, the child would have been asked what was happening and if appropriate, would have been reminded of his or her right to stop the interview process and stop participation in the study entirely if he or she desired. If the child had stated he or she simply needed a break then conversation would have either stopped or shifted depending on the child and what he or she said the needs were. Any child wishing to end participation in the study would have been reassured that it was fine to do so and would have been reminded that there were no punitive consequences for doing so. Options for counselling support such as individual counselling or bereavement support groups (both offered through Victoria Hospice) would have been offered to the child in discussion with the parents. The researcher would have encouraged parents and children to jointly make the decision about whether to follow up with any of those support options. It is important to note that none of these contingency plans were required when the actual interviews took place. I

did not observe any behaviors that would indicate that a child was struggling during the interview process.

Concerns regarding the impact of the research on participants

Oosterheld, Fogas & Rutten (1998) query the need for follow up with the child upon completion of the research. "Should we require routine observation of children who are research subjects for 30 minutes after any research procedure to assess their degree of comfort and provide built-in psychological interventions?" (p.685). I felt that follow up with children participating in this particular research was essential. I did not believe that a 30-minute observation period immediately following the research procedure was sufficient however, as some reactions may take longer to surface. Based on my own clinical experience and incorporating Cody's (1991) time frame in his study on grieving a personal loss, I thought it appropriate for the researcher to place a call to the parents one day and then one week following the research interviews in addition to the 30- minute observation period immediately following each interview. The purpose of the phone calls was to check on possible reactions (both positive and negative) that the child had experienced from participating in the research. Parents and children were also encouraged to get in touch with the researcher before the proposed time frame if any problems or concerns arose. It should be noted that anecdotal information from the phone check-in was not included as part of the data gathering process as the purpose of the calls was just one of many ways the complex ethical needs of this research study were addressed. I felt it was important to inquire about all immediate family members when doing the phone check-in, as I recognized that even if the child who participated in the research was not impacted negatively, someone else in the family may have been. One family member

talking about his or her loss process may activate another member's loss process in a way that was not anticipated by the family beforehand. In any situation where either the family or the researcher identified concerns, proper referrals to community agencies (such as Victoria Hospice) would have been made if the family desired. The researcher had also obtained permission from Victoria Hospice's bereavement department that they would provide one on one counselling or group support to any participant or family member should the need arise as the result of participating in this research study. It would have been the family's decision whether they choose to act upon these referrals. It is important to note that although it is ethically essential to have these contingency plans in place, none of the children or other family members who participated in this particular study required further follow up as a result of participating in this research on children's experience of loss following the death of a significant adult.

Before giving more detailed information about the follow up phone calls it is necessary I introduce the participants by name, Jane, Sean, Bobby and Holly. Further detail to the participants can be found in Chapter IV (p. 69-71). With the first follow up call with Jane's mother, she reported that no upset had surfaced for anyone. She said there had been some discussion the previous night by family members about what Jane had talked about in the interview and Jane had been happy to provide some examples. She also stated that the children had requested to go to their grandfather's gravesite. Jane had been playing when I called. She reported that she was doing fine and did not need any follow up. During the one-week follow up call with this family, Jane's mother reported that there were still no concerns and that in fact it had been several days since Jane had mentioned the experience. Again Jane reported that she was fine and had no

need for follow up. I let her know this would be my last call and thanked her again for participating in the research study.

In speaking with Bobby and Sean's mother the day following the interview, she also reported that no upset had surfaced for anyone. She said the boys had checked out with her whether or not it was o.k. to talk about some of the things they had mentioned and she supported them by reaffirming that all that they had to say was important. She said that the boys felt "really comfortable with me" and that the meeting to talk about the study beforehand had contributed to that. I spoke with Bobby who reported he was doing fine and did not need to talk further with anyone as a result of participating in the interview. I let him know I would be calling again in one week's time to check again. Sean was unavailable as he was out of town with a sporting team. His mother said he had not raised any concerns nor did she have any about him. During the one- week follow up call I was able to speak with both Bobby and Sean. Bobby again reported that nothing had come up for him and that he had been "really busy" all week. Sean also reported that he was doing fine, did not feel the need for any further follow up and he referred to participating in the interview process as both "really good" and "great". The boys' mother reported her impression that the boys had been "empowered" by the experience of contributing to the research. She said that all were surprised by the "gift" found in being a part of this research study. From her perspective, the gift was that the boys were able to reflect back on their loss experiences, see their own resilience within them and recognize how far they had come since then. She also reported that both boys continued to initiate conversations about what they talked about during the interviews off and on over the past week.

In the first follow-up call with Holly and her mother, Holly said that she was doing fine and did not have any concerns. Holly's mother described Holly as being her "usual cheery self" and that she had not mentioned the interview at all other than to talk about some of the things she liked in the playroom. In the second follow up call Holly again said that she was doing "fine." I thanked her for her participation and let her know that it had been very helpful. She said "oh good." I spoke with her mother who also reported no concerns. She stated they had hoped their participation would be helpful and I assured her it had.

The issue of power

In order to address the issue of power that inherently exists between adult and child, the interviews were conducted following the guidelines laid out by Knapp (1997), Baumann (1994), and Tammivaara & Enright (1986). These researchers recommend resolving the power differential between adult and child through giving the locus of control to the child. Some sense of control of the interview is shifted to the child by the researcher asking open-ended questions and then following the child's lead. Having materials present (in this case drawing materials) for the child to use during the interviews helps the child to create some distance between the research subject and him or herself if desired, while still being able to participate in the interview process.

Eder & Corsaro (1999) provide an important perspective that must be considered. These researchers state that, "Young people become empowered when they see how they can influence daily interactions through their worlds and actions, as ethnographic findings reveal the ways in which their worlds and actions contribute to shared meanings"(p.524). Therefore, a child's contribution to involvement with this research

process could be considered empowering by some. In fact this idea was supported by one of the parent's whose children participated in this study. It was her observation that her children were "empowered" by the experience.

Ethical considerations of the researcher

A final ethical consideration was the impact of the research on the researcher. The researcher followed guidelines provided by Rowling (1999) that suggest that the researcher gets ongoing supervision while doing the research. Rowling (1999) also used a personal journal which was used for debriefing purposes and helping the researcher to address personal issues that came up through doing this research that had the potential to impact the analysis of the findings:

The journal entries performed valuable technical and supportive functions in research on this emotionally charged, sensitive issue. The journal keeping facilitated the documentation of my reflexivity - a vital technique for qualitative researchers identified by numerous authors- as a means of highlighting theoretical perspectives, preconceptions and assumptions. This fulfills a technical function helping to maintain rigor in the research. But in the research cited here, journal keeping also provided data on my emotional reactions during the research. (p.176)

I found writing in a journal following each interview very helpful. It gave me a place to express my feelings, thoughts and reactions to the interview. This provided me a way to release personal reactions and to debrief. It also provided information to reflect upon before doing the next interview. My research journal proved to be an important communication tool to myself.

Other ethical considerations

In addition to the extraordinary ethical considerations required when using child participants, this research also adhered to more typical standards required for the protection of research participants. The study was reviewed and approved by the Human Research Ethics Committee with the University of Victoria. Victoria Hospice's research committee reviewed the research proposal and consented to use of their bereavement data base information as a resource for sampling for the study. I explained to family members that confidentiality of the child would be protected throughout the research study and in any final documentation the study produced. Any written documentation uses fictional names to insure privacy of the children and families is maintained. Data was secured in a locked filing cabinet and was only viewed by the researcher, her research supervisor and her committee as appropriate. In order to protect the confidentiality of the child, no specific information about that child's interviews was to be shared with the parent unless risk of harm to the child was revealed. Again, this was not something that was an issue with the four participants in this study. Upon acceptance of this research by the University of Victoria, the transcribed interview documents will be shredded and the tape recordings destroyed.

Summary.

This chapter provides the methodological framework followed in the current study regarding bereaved children's loss experiences following the death of a grandparent. In addition, a framework for rigor is provided as is an in-depth consideration of ethical issues that arise in research with child participants. The following chapter will convey the findings of the study as supported by text from the participants.

Chapter IV

Presentation of Findings

Introduction

The central purposes of data analysis within the descriptive-exploratory research method are to identify themes and to construct a description of the phenomenon. Parse (1985), refers to this process as analysis-synthesis.

“Analysis-synthesis is a process of separating the themes according to the major elements in the objectives, examining these elements, and constructing a unified description of the phenomenon as lived by the subjects. The major themes are transformed to a higher level of discourse in the move from the subject’s language to the language of the researcher” (p.94).

As stated in Chapter III, in order to come to the findings of this study, I worked with the data in a number of ways. Parse (2001) provides steps for researchers to follow for analysis-synthesis using descriptive-exploratory methodology. The steps are:

1. Identifying major themes according to the objectives in the language of the participant(s).
2. Reading the transcribed text of the interview while listening to the audiotape.
3. Identifying and separating major ideas contained in the data about the phenomenon of concern.
4. Identifying and separating major ideas common to all participants.
5. Naming representative themes of the major ideas common to all participants.

6. Stating the major themes according to the objectives in the language of the researcher. (p.58-59).

I will now describe how I carried out those steps using the data from the interviews conducted in this study. I transcribed the interviews verbatim (with the exception of changing participants' names). Next I listened to the audiotapes while following along with the transcripts. While doing this several times, I made pencil marks where the individuals answered the questions that arose from the three objectives of the study. Next I created three documents, each one representing one of the objectives of the study. In each document, I placed all participants' major ideas reflective of the objective. I reviewed these documents several times, searching for ideas that were common to all the participants and again made pencil marks on the pages where I noted ideas that were common to all. Following that, I created three new documents, each one again reflected an individual objective this time however, each contained the major ideas common to all participants. I reviewed these documents by dwelling with the content of the major ideas. For example, if there were two major ideas contained in an objective, I would consider ways to bring the two ideas together in order to be reflective of the experience as a whole. I would work with the wording of the theme until it honored the language the children used to describe their experience and additionally reflected the theme as a whole. This is how the theme for the objective was revealed.

The findings of this study are represented in three themes. While it is recognized that the three themes are in fact interrelated, each on its own offers a meaningful aspect of the whole experience of the phenomenon of loss as offered by the participants in this study. In accordance with Burns' (1988) third standard for rigor, analytical preciseness,

the researcher is required to demonstrate the decision trail to the findings. To adhere to this standard, the findings of this research will be presented by first offering the major ideas common to all participants as reflected in each objective as that is what I first identified. The major ideas common to all participants ultimately led to identification of the themes addressing each objective. Following presentation of the major ideas common to all participants, I will identify the theme for that objective as it exists in the language of the participants. The final step is the presentation of the theme in the language of the researcher. A summary of findings are presented in a table located at the end of this chapter (p.82).

Participants of the study

In accordance with Burns' (1988), criteria of descriptive vividness in rigor, before presenting the findings it is essential to provide some detail on the participants and the interview process as it occurred in this study. Participating in this study were four children between the ages of eight and twelve years of age. There were two males and two females. Each child had experienced the death of a grandparent between nineteen months and thirty four months previous to the date of the interview. For three of the children it was a grandfather and for one child a grandmother. All of the children's grandparents had been diagnosed with cancer and had registered with Victoria Hospice for palliative care at some point within their disease process. Data collection occurred over the months of November, 2003 – April, 2004. I will now introduce the participants in detail.

Jane

Jane was eight years of age at the time she participated in the interview. Her grandfather had died of cancer nineteen months earlier. I first met Jane and her family at her home on October 20th, 2003 to discuss the study and go over consent forms. During this meeting the family agreed to participate. Jane appeared enthusiastic about being involved in the study. It was cool and rainy on the day of Jane's interview. She arrived confidently into the playroom. Our conversation was a mixture of seriousness and humor. Jane chose to talk and then towards the end of our half hour together, decided she would also like to draw a picture about her grandfather. Following her drawing, she took some time to describe it to me. Jane's drawing consisted of a heart divided in two sections. One side had a picture of her face and above the word "Me". The other side of the heart had a drawing of her grandfather's face with what she described as "explaining" words written above it. The explaining words were "kind hearted, kind and funny". Above the explaining words Jane had written the word "grandpa". Both facial portraits were smiling. Jane's description of her drawing to me consisted of a summary of the picture. It is interesting to note that her drawing was also a summary of the conversation we had just finished.

Sean

Sean was twelve years of age at the time of his interview. His grandfather had died of cancer thirty four months earlier. Sean had experienced multiple losses with four neighbors dying in a six month time frame around his grandfather's death. Sean participated in this study along with his brother Bobby. I first met Sean on December 1, 2003 at Victoria Hospice. As with Jane, this meeting was to discuss the study and consent

and resulted in Sean volunteering to participate. Sean shared that he had participated in two previous studies, he felt confident to be a part of this study. On the day of his interview Sean, choosing to talk, was relaxed in the playroom and reflected deeply and spoke extensively on his experiences of loss following his grandfather's death.

Bobby

Bobby was nine years of age at the time of his interview. His grandfather had died of cancer thirty four months earlier. Bobby, like Sean had experienced the death of four neighbors in a six month time frame around his grandfather's death. As stated earlier, I initially met Bobby along with Sean at Victoria Hospice. Bobby was also agreeable to participating in the study and we met again on January 21, 2004, a typical winter afternoon in the city, at the playroom to do the interview. Bobby chose to talk and was very thoughtful throughout the interview process, taking his time as he reflected and spoke openly about what the loss of his grandfather meant to him.

Holly

Holly was ten years of age at the time of her interview. Her grandmother had died of cancer thirty two months earlier. I first met Holly and her parents in their home on April 15, 2004. Holly was quiet during the meeting but was clear that she wanted to participate. She particularly liked the idea that she would be contributing to help other adults and children understand what it is like for children who experience the death of someone important. Before I left her home that day, she showed me where her family has some of her grandmother's ashes located in a special garden in their yard. On the day of her interview in the playroom, Holly chose to talk although she is also a skilled artist. She shared her experiences and thoughts about what it has been like for her following her

grandmother's death. During our half hour wind down time together she was thrilled to discover some musical instruments in the playroom and had a wonderful time creating sounds.

Objective one

The first objective for this study is to describe the meaning related to bereaved children's experience of loss following the death of a significant adult. This objective flows from the first principle of Parse's theory of human becoming. That principle states, "Structuring meaning multidimensionally is cocreating reality through the languaging of valuing and imaging" (Parse, 1992, p.37). This principle purports that people make meaning of an experience through their own unique lens and they share that meaning with others through the values they live, and the language they speak. In working with the data, two major ideas common among all participants that reflected this objective were identified. These major ideas, description of loss and permanence of loss will be discussed and supported from participant's statements contained in the data. Each major idea is introduced through a quote from one of the participants and is then further supported with excerpts from all of the children.

Description of loss

Bobby: "Well at first ...it was sad, like for the first couple of days ...and then you kind of get over it after awhile and then ... sometimes you think back and you have those little moments you have as sad times again...."

Each of the participants provided a description of what it has been like for them since their grandparent died when they answered the question "what has it been like for

you since (grandparent) died?” These descriptions reflected the emotional content of the loss for each individual.

Jane shared, “It’s been very sad” and went on to explain what was sad about the experience for her, “That he was my only grandpa left and I didn’t want him to die.”

Bobby shared how the loss impacted him immediately after his grandfather’s death and how it still affected him at the time of our interview. “Well, it kinda does make me a little sad but then you just get that warm spot ...” In reference to the warm spot, Bobby described “it’s just a good feeling”.

Sean talked of the disbelief he experienced following his grandfather’s death. “... I didn’t really believe it at first. It was like it couldn’t have happened ... it was really sad. ... I just kinda couldn’t believe it at first.” “It’s kind of like ... when I go there after he died ... I expected him to be there sitting down in his chair. Say “how’s it going” and stuff but when he’s not there it just ... you feel empty inside.”

For Holly the experience was about missing the excitement that her grandmother provided in her life. “Kinda lonely ... my grandma, she used to live downstairs and whenever I came downstairs it would always be a big deal and she would always say “hi” but now ... all we have is a student who lives downstairs ... and ... it’s just lonely, it’s boring.” Each participant’s description of loss contained the anguish they experienced following the death of their grandparent with such words as sad, lonely and empty.

Permanence of loss

Holly: “She’s in the dirt.”

The second major idea addressing the first objective arises from each participant expressing their realization that death is permanent.

Jane talked of a time when she saw a movie in which a grandfather came back from the dead “whenever I think about the “Bluebird” and I remember when mommy turned the t.v. off and said that if grandpa came back, he would have to leave.” She described herself as feeling better knowing that grandpa would have to leave.

Bobby shared how a book had helped him understand the permanence of this loss, “Well ... my mom has a book and it’s about when things die and it talks about when people die ... like you can feel sad but not to be too sad at times because they just have their time that they have to go.”

Sean talked about knowing his grandfather was dying and what that meant, “Well when you’re that sick and there’s no way of recovery you know. Like he was in ... such a critical condition. Then ... the couple of days later we all sat down on the couch and mom was like you know ‘grandpa was really sick and he just stopped breathing’ ...”

For Holly the understanding was demonstrated through her concern that her grandmother would die on Holly’s birthday as her grandmother was very ill during that time. “Well, ...it was around my birthday and ... so I was kind of afraid that she would go when it was on my birthday and everyone would be so sad ... it will be like a bad day for everyone for my rest of my life and that stuff. And it’s not that it would be bad but it’s just that I don’t want to know that grandma died on my birthday. I don’t think we would celebrate my birthday on the same date for the rest of my life.”

Each of the children shared their understanding that separation from their grandparent was permanent through describing their explicit and implicit knowledge that this death had permanently affected their lives and that there was no way of changing it back, what had happened was not reversible for them.

Theme one

Arising from the major ideas common to all participants, the theme then for the objective to describe the meaning related to bereaved children's experience of loss following the death of a significant adult is:

Sadness deepens with awareness of the permanence of death

This theme was identified through consideration of the two major ideas, description of the experience and recognition of death's permanence, and how to weave them together to reveal the whole experience as identified by the participants. Special attention was paid to the language the participants used in describing their experiences as well as what the underlying common meaning of the experience was in order to identify the theme. The theme in the language of the participants is offered in concrete language as that is reflective of how the children themselves spoke. I wrestled with the identification of the theme and the language until I felt the written words resonated with the spoken words I had heard during the interviewing process.

The next step in analysis-synthesis requires the researcher to move the theme from the language of the participant to the language of the researcher which involves moving the language to a more abstract level. In the language of the researcher then, the meaning of bereaved children's experience of loss following the death of a significant adult is:

Anguish in separation mingles with embracing of unalterable circumstances

Moving the theme from the language of the participants to the language of the researcher was done in a number of ways. First I consider the individual words contained in the language of the participants. I asked myself, "what is another way of saying this?" and "what is a more abstract way of saying this?" For example, shifting the word "sadness" to

“anguish”. As I thought of a particular word that was more abstract, I then asked the question “is this word reflective of the participants’ meaning?” An additional question asked was “is this word reflective of the experience as a whole?” I then used a thesaurus to see if there was another word that held the same meaning but seemed to fit the whole tone of the theme. I chose language which I believed was best representative of the meaning of the theme. I then adopted human becoming theory’s use of the “ing” gerund to be reflective of the theoretical belief that processes are ongoing as can be seen in the word “embracing”. Again, I wrestled with both identification of the theme and wording until I felt both resonated with what I had heard spoken during the interview process.

Theoretical connectedness

In keeping with Burns’ (1988) fourth standard for rigor, theoretical connectedness, I will now demonstrate the connection of the identified themes to the theory of human becoming. To explain coming to this interpretation consider that Parse (1992) states, “meaning continuously changes as humans grow more diverse and as different experiences create new images” (p.37). For Parse, the word images or imaging refers to knowledge, both explicit and tacit. The theory states that as people experience something new they cocreate through previous experiences, people, activities and things new knowledge about that experience. As Parse’s (1992) theory of human becoming posits, people cocreate new knowledge continuously as they move through their lives. The participants of this study talked of how the death of someone of great value in their lives left them feeling bereft. It was through loss that they came to know the permanence of death and the sorrow of separation. Sean: “... when it’s recent you feel sorry about it

... then later on you just kind of try and forget about it and get on as if nothing happened kind of a thing ... don't let it affect your schoolwork or anything..."

Objective two

The second objective of this study is to describe how relationships (as defined by people, things or activities) unfold for bereaved children experiencing the loss of a significant adult through death. It is based on the second principle of Parse's theory of human becoming which states, "Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing, enabling-limiting while connecting-separating" (1992, p.37). This principle speaks to how humans relate in paradoxical rhythms. In any given interaction one both reveals and conceals who they are. In relation with others, one is always making choices that enable certain opportunities while limiting other opportunities. Additionally, humans move towards and away from other persons, projects and situations all at once thus both connecting and separating at the same time. Again, to distinguish how the theme for this objective was identified, I will first begin by identifying the major ideas common to all participants. These major ideas are doing activities with their grandparent, memories of their grandparent and recollection of their grandparent through others. The others were defined as people, things or activities.

Activity with grandparent

Jane: "It made me feel happy that I got to do things with him."

Each of the children shared extensive details of activities they had spent doing with their grandparent when answering the question "what is important to you about (grandparent)?"

Jane talked of a special trip, "... we went to West Edmonton Mall with him and he paid for all of our tickets."

Bobby shared about times spent sitting on grandpa's lap, "Well ... he was really nice you know and ... when I was little he used to let me sit on his lap on his rocking chair and we would just, he would tell a story sometimes."

Sean enjoyed spending time with his grandfather in his grandfather's workshop, "... it's like ... me and my grandpa we were really close so like we'd always go over there to do something. We'd go down into his workshop or whatever, just play around."

For Holly time with grandma was about learning things, "She used to always give me, well she didn't give me anything but she always ... let me see what she was doing and she taught me how to knit but I forgot ... and she taught me a lot of other things and she taught me how to make ice cream with peanut butter."

Each of the participants offered up the varying activities they participated in with their grandparent who had died when asked what was important to them about their grandparent.

Memories of grandparent

Bobby: "Sometimes, if he was on the television we [Bobby and his brother] would just go outside and play and we would come back in and he would let us have some television time."

Another major idea contained within the data was that of memories participants had of their grandparent. Jane talked about what was most important to her regarding her grandpa. "That they don't yell at me, grandpa never did yell at me. And when he said "Jane and [brother] stop fighting he said, 'I'm going to kick you out of the house if you

don't stop fighting. So he was funny even when he was serious." In her drawing she included what she defined as "explaining words" about her grandfather. These explaining words were, "kind hearted", "kind" and "funny". The words Jane placed on her drawing succinctly reveal what she valued about her grandpa.

Bobby also shared how he remembers his grandfather. "Well, I remember him as kind of a funny guy ... well he was funny and he was fun to play with too. He would never cheat at games. He was always a fair player ... and he was nice about some things, like if he won a game he wouldn't be all braggy and stuff, ... he was really nice about it; but he never really wanted to stop playing either."

In our conversation together, Sean shared ways he remembers his grandfather, "When I was younger they would have this big red toy box. Grandpa would always bring it out and play with the stuff inside. So ... once I brought that out again and I looked at the toys and stuff that we played with ..."

For Holly an important fact about her grandmother was "That she's not one of those grandma's that just say "do this right now because I don't have any time; she show's you how to do the thing you don't know how to do and doesn't yell at you if you've done something wrong."

Each of the participants freely shared cherished memories of their grandparents when asked "what is important to you about (grandparent)?"

Recollection through others

Holly: "Well we always bring rocks and that kind of thing ... painted rocks because she liked those and we give her favorite flower, I think it's a lily, then we just do a memory thing about her using words ..."

The final major idea common to all participants regarding this objective was the idea of continuing to have a sense of connection with the person who has died despite their understanding that their grandparent was no longer physically present in their lives. For the participants this recollection happened through other events (people, things or activities) which occurred and reminded the children of their deceased grandparent.

From Jane, “And there’s this movie that reminds me of him, it’s called the Bluebird. Because Shirley Temple and her little brother had to go up to the cemetery and they went back for the grandma and grandpa but they died and they started crying when they left because the grandpa liked to finish this carving and the grandma wanted to cook something but since, ... Shirley and her little brother left, they had, they went back to sleep and I... wanted my grandma and grandpa to finish what they wanted to do.”

Bobby talked about his recollection when he passes the place where his grandfather is buried, “... sometimes I have a hockey game down at Juan de Fuca and that’s where he was buried and when we drive by there ... I just remember where his grave is ... so I remember.”

Sean stated, “Well, that I also constantly visit my grandma in the same house...like we do activities and stuff ... it’s important that I go back to the place where [grandpa] was.”

Holly talked about how the things her grandmother taught her are still useful to her today. “That they [things grandmother taught] help me out later, like now, like one thing she taught me, we were supposed to do for a charity, a recipe that they could use something that they may have and I used the ice cream and peanut butter thing.”

It can then be seen how each participant described how through other activities, people or things, the memory of their grandparent continues on for each of them.

Theme two

Synthesizing the major ideas common to all participants regarding the objective to describe how relationships (as defined by people, things or activities) unfold for bereaved children experiencing the loss of a significant adult through death, reveals the theme in the language of the participants as:

Time spent doing things and with others provides memories

This time creation of theme required weaving together three major ideas instead of two. The steps to do this were the same as previously identified. Care was taken to be representative of the language the participants used as well as to be representative of the experience as a whole.

The theme then shifted to the language of the researcher is:

Relationships unfolding through cherished activities and being with others

This theme was shifted to the language of the researcher using the same methods described earlier.

Theoretical connectedness

Parse's (1992) second principle addresses how humans cocreate rhythmical patterns of relating through living the paradoxical unity of revealing-concealing, enabling-limiting while connecting-separating. The theme for the second objective reveals how these participants are cocreating the rhythmical pattern of connecting-separating. According to Parse (1992):

Connecting-separating is a rhythmical process of moving together and moving apart. In moving together, with one phenomenon, the individual moves away from other phenomena. In moving together, there is both the closeness of togetherness and the distance of moving apart with the same phenomenon.

(p.38)

The connecting-separating rhythmical pattern is identified through the participants sharing how they remain connected with their grandparent through memory of activities shared together and through being with people, doing things or doing activities that remind them of the person who died. The connection is able to continue as the children paradoxically contend with the physical loss of the person in their lives. Jane shares some of her important memories, "About how nice he was... that he loved me ... he loved me very much".

Objective three

The third objective of the study is to describe bereaved children's changing perspectives on their desires, hopes and dreams following the loss of a significant adult through death. This objective flows out of Parse's third principle within human becoming theory. The principle states, "Cotranscending with the possibles is powering unique ways of originating in the process of transforming (1992, p.38). This principle addresses the way that humans are able to shift their experiences in the midst of change. Humans go through a process of pushing-resisting experiences (powering) which may ultimately lead to "shifting of views of the familiar as different light is shed on what is known," (Parse, 1992, p.39). The shifting of views is what Parse (1992) refers to as "transforming" (p.39).

The major ideas common to all participants that address the final objective are hopes and desires and the experience of being watched over. Once again, from the major ideas the theme will be identified in the language of the participants and then presented in the language of the researcher.

Hopes and desires

Jane: "I'd go back to West Edmonton Mall with him."

Each of the research participants answered the question "how would you like things to be different?" Each of the children talked about how they would like things to be the same as they were before the death occurred.

Jane said, "I wish that in the future that grandpa could come back." She went on to say that "I would do everything with him" if he did.

Bobby also expressed a hope that his grandfather would still be alive. "I do hope he would still be around."

Sean wanted things as they were before, "I would just like to get on as life was before everything happened."

Holly too wanted her grandmother alive again, "Well that she was alive" and again, she wanted to do "all that stuff that I told you before" in terms of activities that she had done with her grandmother.

One can see that all the participants expressed a strong yearning to have their grandparent and in fact life itself back to the way it had been before the death occurred.

Watching over

Sean: "Like when I'm feeling down or miserable or something like when I'm not feeling at my best then I remember that he's there kinda pulling for me, that helps."

Each of the participants also shared a belief that their grandparent was still caring about them. It was described as “watching over” and is included under this objective because it speaks to how bereaved children are able to transform their experience of loss from anguish at separation to a continuation of their relationship with their grandparent.

Jane described her beliefs as follows, “I think he’s watching me and [brother] from up in Heaven.” She went on to add, that Heaven is “A place that you get to have anything you want and you’re not allowed to be sad.” Jane feels that while in Heaven her grandfather is “watching t.v. on his new white feather bed.”

Bobby shared how he experiences his grandfather helping him out in times of difficulty. He had taken a fall while mountain biking and expected to be hurt. “Well once I was actually mountain biking ... I went off the jump ... I went sideways and I landed on my arm, felt like it was broken but it wasn’t and it got better ... it didn’t hurt as much as I thought it would ... it just barely hurt at all really ... it didn’t bother me at all.”

Sean talked about making things in his grandfather’s workshop and placing them on his grandfather’s chair. “It feels as if that he’s there for that bit and that like ... he’s watching me or something.” “It’s nice cause it’s like he’s there again.”

Holly talked about at one time wondering if her grandmother lived on a cloud. She saw the shape of a “J”, the first letter in her grandmother’s name, in the clouds and felt compelled to say “Hi.” “Well, I thought that it was a place, like you know how clouds sometimes shape things ... sometimes shape like pools and stuff, I thought maybe grandma lived on a cloud like cloud nine or something. So I just waved, I don’t know why.”

From the above comments one can see how each of the participants continues to feel cared for by their grandparent despite the physical separation from that person.

Theme three

The third theme addressing the objective, to describe bereaved children's changing perspectives on their desires, hopes and dreams following the loss of a significant adult through death in the language of the participants is:

Wishes to undo the past mingle with ongoing relating with one who has died

Again, this theme arose from connecting the major ideas together to represent the experience as a whole. The theme expressed in the language of the researcher then becomes:

Yearning for what was dwells with continuing presence in the now

The theme as represented in the language of the researcher is once again more abstract but continues to be reflective of the major ideas common to all participants and is representative of the experience as a whole as it was described by those participants. The language of the researcher also is representative of ongoing experience, in congruence with assumptions of human becoming theory.

Theoretical connectedness

Support for interpretation of this theme is found in a concept contained within the third principle of human becoming theory, "One's patterns of relating, then are both the same and different all at once; threads of what was and is weave with the new and can be recognized in the fabric of one's life. This is transforming" (1992, p.39). The participants of this study wove their previous experiences with their grandparent into how they continue to relate with them now and transformed the feeling of separation into an

experience of caring that goes beyond physical limitations. As Sean describes, "... you feel ... it's kinda like a voice inside your head that he's there and you kind of imagine that."

Summary.

The following table presents a summary of the findings of this study which asks the question what is the meaning of loss for bereaved children following the death of a significant adult? The table presents the findings as representative themes in both the language of the participants and the language of the researcher.

Table 1 Presentation of findings

Objective	Language of the participants	Language of the researcher
Objective 1	Sadness deepens with awareness of the permanence of death	Anguish in separation mingles with embracing of unalterable circumstances
Objective 2	Time spent doing things and with others provides memories	Relationships unfolding through cherished activities and being with others
Objective 3	Wishes to undo the past mingle with ongoing relating with one who has died	Yearning for what was dwells with continuing presence in the now

The next chapter will present how the findings of this study relate to previous knowledge about children and loss along with discussing where new knowledge has been developed. The chapter will also consider what implications for practice the findings of this study provide. Finally, based on the findings of this study, directions for further research will be offered as well as limitations of this study explored.

Chapter V

Discussion of findings

Introduction

In keeping with Burns's (1988) second dimension in the final standard of qualitative research, heuristic relevance, the researcher demonstrates the findings relationship to an existing body of knowledge. Given that, the findings will now be explored from existing research on loss. As the theoretical perspective used in this research was that of human becoming; I will begin by reviewing existing literature on loss that also used that perspective. From there, I will compare the findings with other literature on the phenomenon of loss that arises from differing theoretical perspectives.

Human becoming theory

Cody's (1991) phenomenological study of grieving a personal loss revealed the structure of the lived experience of grieving as "intense struggling in the flux of change, while a shifting view fosters moving beyond the now, as different possibilities surface in dwelling with and apart from the absent presence and others in light of what is cherished" (p.64). The findings based on the experience of the loss of a grandparent in this study resonate with Cody's findings. The children spoke of the anguish they experienced through separation from their beloved grandparent. For example from Sean, "It's kind of like ... the sadness and stuff is trapped inside you so you want to get it out of there, like exterminate it. Well ... it's as if the ... grief is in your tears and crying is a natural way of getting it out." This reflects Cody's finding "intense struggling in the flux of change" (p.64). The current research findings also reflect how the children continue relating to their grandparent through memories of activities shared, places and other people. Holly

shared, "... she liked to watch soap operas so I got interested in that. It was fun because I didn't understand them very well, on commercials she would always tell me what they meant ...". This concept is reflected in Cody's structure "as different possibilities surface in dwelling with and apart from the absent presence and others" (p.64). The participants of this study also shared their experience of their grandparent continuing to care for them despite the lack of physical presence of that person from their lives. This concept matches Cody's structure where he reflects "shifting view fosters moving beyond the now" (p.64). The participants revealed how they transformed their relationship beyond physical limitations to feeling cared for by their grandparent who they feel continue to watch over them. As Jane said, "I think he's watching me and [brother] from up in Heaven."

Pilkington (1993) also conducted a phenomenological study of the loss of an important other. The structure of grief revealed in her study was "an anguished suffering in devastating void amidst consoling movements away from and together with the lost one and others while confidently moving beyond personal doubts" (p.130). The findings of the current study also reflect some of the structure that Pilkington (1993) identifies. The children described their experience of loss as a mixture of many emotions, sadness, disbelief, emptiness, and loneliness. As Jane succinctly says, "It's been very sad." These descriptions match Pilkington's "an anguished suffering in devastating void" (1993, p.130). Her structure, like Cody's (1991), both reflect the rhythm of moving away from and toward the person who has died through others. As already discussed in conjunction with Cody's (1991) findings, the participants of this study revealed how they continue to remember their grandparent through activities, places and other people.

Where the difference lies between Pilkington's structure and the findings of this research are within the concept "confidently moving beyond personal doubts" (1993, p.130). None of the participants in this study talked about personal doubts as part of their experience of loss. A possible explanation for this is that the death the children experienced in this study was the death of a grandparent. Had it been the death of a primary caregiver such as a parent there might quite possibly have been significant role changes occurring. Also, for the participants of this study, there were remaining grandparents alive. Although one of the children spoke of it being her last grandpa, she still had a remaining grandmother alive. It is possible that the role of grandchild would have shifted more if there had been no remaining grandparents.

Other loss research

In a phenomenological study by Dietrich, McWilliam, Ralyea and Schweitzer (1999) in which five women offered their experience of loss following the death of their mother, seven themes were identified, recalling, holding on, saying goodbye, longings of the heart, shifting patterns of relationship, recreating the dialogue, and honouring our mothers/ourselves. One theme, "recalling" from the findings of their study resonates with the findings of the current study. That theme is "recreating the dialogue" and conceptualizes how the participants of the Dietrich et al study experience an ongoing connection with their mother despite her death. According to the researchers, "The women spoke about physical sensations, hearing their mother's voice, and spontaneously 'speaking with' their mother, either out loud or in their thoughts" (p.88). The four participants of the current study also revealed how they have continued a connection with their grandparent. They spoke of it in terms of being 'watched over' by the grandparent.

The participants talked of experiencing their grandparent caring for and assisting them at, specific times of need. Bobby talked about a hockey game he was in. "... I was playing hockey and ... I was little and I couldn't shoot that well ... so I came in and I shot it and it was a good shot and [I thought] did I do that? ... That was only a once in a while sort of thing and actually it was a very important game."

In Galloway's (1990) study of young adults' reactions to the death of a parent, the findings of the current study resonate with one aspect of the findings of that study. Galloway found that the nineteen participants of her study described an immediate sense of loss as "being alone deep inside, sad, or devastated" (p. 901). The children of the current study described their own experiences of loss as a time of sadness, disbelief, emptiness and loneliness. These descriptions resonate with the nineteen adults' descriptions found in Galloway's (1990) research. Other aspects of Galloway's (1990) study that do not match the findings of the current study were, how participants described the physical impact of grief, and how the death of one parent impacted the relationship with the remaining parent. The four participants in the current study did not speak to physical reactions of their grief nor did they experience the death of a parent which influenced the relationship with the remaining parent.

Processes of grief

Rando (1984) describes three main categories to the cognitive and intrapsychic processes of grief. They are decathexis, development of a new relationship with the deceased and formation of a new identity. While all the categories are separated, Rando (1984) acknowledges that the processes are interdependent. To begin, decathexis is a concept from psychoanalytic theory and addresses the fact that after a death there is a

need to accept the loss in the bereaved person's external world and adapt that same knowledge and acceptance into the bereaved person's inner world. "Thus, decathexis is a crucial intrapsychic procedure that must be accomplished in order for the bereaved to successfully resolve the loss and have the unattached emotional energy to invest in subsequent relationships" (Rando, 1984, p.77).

According to Rando (1984), the next category in the grief process is the development of a new relationship with the deceased. The idea behind this concept is that although one understands that the person has died, it does not constitute the end of the relationship. The bereaved person finds new ways for the relationship to continue. Rando offers suggestions of ways this is done, "Some possibilities are rituals, anniversary celebrations, prayers, commemorations, memorializations, and healthy identification" (1984, p.78). Silverman (2000), in her writing on a framework for loss also offers the notion that bereaved adults and children find ways of constructing an ongoing relationship with the person who has died. This notion is supported through research conducted by Silverman & Worden (1992 a, b) which provides evidence that children seek to and do find ways of staying connected with the person who has died. According to Silverman (2000), this relationship is both comforting and sustaining (p.33).

The final category according to Rando is formation of a new identity. When an important someone dies, parts of the person who remains also die. The parts that die consist of roles that existed within the relationship with the deceased person. Rando states, "A perspective is needed on both what has been lost and gained as a consequence of the death. That which has been changed ... must be recognized and grieved for; that which continues must be affirmed; that which is new must be accommodated" (1984,

p.78). Again, Silverman (2000) echoes the ideas that Rando puts forth in Silverman's own framework. She also offers that the bereaved develop a new sense of self as part of their loss transition. Most notably Silverman states in regards to children "While a changing sense of self is normally a part of every child's life, for bereaved children this process is sometimes accelerated" (2000, p.33).

It is interesting to note that the child participants of the current study offer experiences of loss that fit some of what Rando (1984) and Silverman (2000) constitute as part of processing grief. The children reflected their understanding that the separation they were experiencing from their grandparent who died was permanent. From Sean, "... it would be ... something I would make in his workshop or something that he always enjoyed or I'd like try to invent this and stuff that he'd like; so I'd just set that on his chair. You kind of feel like he's accepting it in a way. Like he is enjoying it ... even though he's not ... physically there." Thus according to Rando's process, they recognized the loss in their external and internal worlds.

The participants of this study also gave extensive examples of how they were continuing their relationship with their grandparent. Holly shared about a common practice the family has, "... we also do it at this place we go to every summer ... We just put a flower near the flagpole because she was born in Canada so we thought that was a good spot." For some of the children the continued connection remained through doing things they had been taught by their grandparent, for others it was through going to specific places and with some it was done through memories and being with other people who knew their grandparent.

Where the findings of this study do not match Rando's (1984) or Silverman's (2000) processes of grief or Pilkington's (1993) structure of loss is in connection to the griever forming a new identity. The child participants did not speak to this as part of their experience. I wonder if this issue is related to concept of self and how that is always evolving for children. It could also reflect how children's roles are always in flux and require ongoing adaptation as they develop. Therefore it does not appear to them to be particular to their experience of the loss of their grandparent.

Research on children's loss experiences

As was demonstrated in the literature review chapter of this study, research focused directly on bereaved children is very limited. A number of studies focused on children's ability to understand death and followed Piaget's developmental theory for cognitive development (Hyslop-Christ, 2000 & Nagy, 1948). Other studies viewed how adults perceive children's ability to understand death (Ellis & Stump, 2000) and whether or not emotional context influences children's ability to understand death (Orbach, Weiner, Har-even & Eshil, 1994).

Worden's (1996) work differed from the above mentioned work. His work was a two year longitudinal study of children who had experienced the death of a parent. His study found there could be a late effect in the bereavement process. Worden found an increase in the number of children who were assessed as at risk for high levels of emotional/behavioral difficulties two years following their parent's death.

The findings of the current study neither support nor dispute the findings of these earlier studies for a number of reasons. Firstly, the methodology used in this study was qualitative. The method of knowledge generation of the previous studies was

quantitative which asked different kinds of research questions than qualitative work. The research question for this study investigated the experience of loss for bereaved children. As experience was the focus, questions asked were shaped to help reveal findings that would reflect the experience of loss for these participants. This means questions that reflect a certain cognitive understanding as tied to a developmental perspective were not asked. It also means that questions about length of time since the death and impact of bereavement along that time frame were also not asked.

The theoretical framework used in this study does not support the concepts of developmental stages or adherence to linear time. The theory of human becoming arises from the simultaneity paradigm which views “human wholeness [as] a patterned configuration, not the sum of particulate attributes. There is no body-mind-spirit triad but rather a human being recognized through patterns in mutual process with the universe” (Parse, 1992 p. 35). In reference to the concept of time passing, Northrup (2002) helps explain human becoming’s interpretation of this concept:

... the human health experience of time passing is understood as a way of becoming that is complex, multidimensional, and paradoxical. Further to its wholeness and non-reducible nature, time passing is considered a lived experience that articulates the richness of the flowing, rhythmical, and unitary process of human becoming in the every-changing human-universe-health interrelationship. (p.320)

Therefore, the findings of the current study neither support nor dispute the findings on children’s cognitive understanding of the concept of death or the impact on bereavement

due to length of time following the death, as the philosophical assumptions of this study do not match the philosophical frameworks of the other studies.

Connections with current children and loss research

These findings do however complement what is already known about children and loss through research. In the study on children's reactions in the early months after the death of a parent by Silverman & Worden (1992a), the researchers identified actions the children undertook to remain connected with their parent who had died. In the second study (1992b), Silverman & Worden looked more closely at how the children maintained the connection. As has already been demonstrated, the findings in the current study also reveal the children maintaining connections with their grandparents through memories, through places and through other things. In addition, the children in the current study revealed that they believe that their grandparent continues to watch over them from another place. Silverman & Worden describe how the children who participated in their second study (1992b) also believed that their deceased parent continued to watch over them. For some of the children in the Silverman & Worden study, this experience was scary. The fear reflected the children's concern that the watching deceased parent would disapprove of some behavior that the child had done. For the four participants in the current study, the experience was one of comfort and support. For example from Bobby, "well, there's some schoolwork that I've done ... before I was having trouble with reading comprehension, the next test I got a perfect score and it just surprised me how fast I changed."

It is believed that the findings of this study contribute to the small body of knowledge existing about children and loss through death by bringing an additional

perspective to what is already available known. More will be said about this in the following section.

What the findings offer

The findings of this study add to limited qualitative knowledge generation of the experience of loss for bereaved children. The findings in this study help to broaden the knowledge base of what is already known through research about bereaved children and provides an alternative understanding beyond how children understand death or how they cope to providing descriptions of children's experience of loss following the death of a grandparent. The findings of this study reflect what these four child participants had to say about their experience of loss in their own wording. That is something that at the time of this writing is not found in existing research on bereaved children who have experienced the loss of a grandparent through death. The findings in this study also offer a philosophical perspective of individual experience. Therefore, the findings do not constrain the process of loss through expected stages or time frames. As Cody (1991) states in his phenomenological study on grieving a personal loss, "Grieving a personal loss is seen as a way of living the now, the what was, and the not-yet-all at once, a view that contradicts theories that specify grieving as a normative set of sequential stages" (p.67). The findings also contribute new knowledge generation toward the theory of human becoming itself. The themes of this study were connected to concepts within the theory of human becoming, building on and supporting the theory itself. In addition, work reflecting that theoretical perspective specific to the experience of loss for bereaved children following the death of a significant adult has not yet been published.

Implications for practice

Findings from the current study provide practitioners with an alternative understanding of the phenomenon of loss beyond children's ability to understand death or their ways of coping. The findings from this study may be helpful to differing practitioners such as child and youth care workers, health care workers, teachers, school counsellors, palliative care counsellors, any professionals who have direct contact with bereaved children who have experienced the death of a significant adult.

Parse's practice methodology

Parse (1992), has created a practice methodology that supports the theoretical perspective of human becoming. An overarching premise of the practice methodology is that "the quality of life for one individual or family may be very different from what constitutes the quality of life for another. The nurse respects each individual's or family's view of quality" (p.39). There are three dimensions to the practice methodology that arise from the three principles of human becoming theory. Each of the dimensions adheres to true presence, a concept defined by Cody (1995) as "an open, loving way of wholly attending to a person" (p.106). The first dimension is illuminating meaning. The practitioner in true presence with someone creates space for that person to reveal the personal meaning of a particular situation (p.39). The second dimension is synchronizing rhythms which consists of the practitioner staying in true presence with someone as they describe the "ups and downs, struggles, moments of joy, and the unevenness of day-to-day living in the now moment" (p.39). The third dimension is mobilizing transcendence which speaks to people moving beyond the moment and pushing forward towards hopes and dreams (p.40).

In relation to the findings of this study, as bereaved children speak of experiences of loss, the practitioner listens for the meaning of the experience for that particular child. Through understanding and acceptance of that meaning, the child will likely feel supported. In addition, the practitioner him or herself, will then have a clearer picture of how this particular child is experiencing this particular loss. While the child describes the experience of loss, the practitioner can attend to the rhythms that are being revealed and help to explore both sides of the rhythm, for example joy-sorrow. The practitioner can also support the bereaved child in identifying what are the hopes and dreams they have in relation to this experience. This exploration could in fact help the child uncover hopes and dreams for him or herself. Where appropriate, the practitioner may encourage the child to share some of the meaning, rhythmical patterns or hopes and dreams with the parent and perhaps the family can do activities together to help support the experience for the child. For example, visiting particular meaningful places the child has identified. The family could work together on a memory box of the grandparent, all adding pictures, words, possessions that are reflective of the person who died. Also where appropriate, the practitioner could also encourage the parent and child to share some of the child's experiences with the teacher or school in order to have the experiences supported in that environment as well.

The findings of this research provide practitioners working directly with bereaved children who have experienced the death of a grandparent the opportunity to be more attuned to children talking about their experiences. Practitioners may listen more attentively as children begin to speak of their unique experiences of anguish through separation, their cherished memories of the person who has died or the experience of

being watched over. The findings of this study may help practitioners to listen to these experiences without judgment, without concern that the children are not in a healthy place in their bereavement because they continue to connect with their grandparent. As Silverman & Worden (1992b) state, "In facilitating mourning, those who work with children may need to focus on how to transform connections and place the relationship in a new perspective, rather than on how to separate from the deceased" (p.503). The practitioner could consider ways of providing opportunities for bereaved children to speak to the many facets of their experience of loss. This could be done with a number of different mediums as well, such as play, art, dance, and music. Goodman (2002) provides information on the use of art in working with bereaved children. O'Toole (2002) explores the use of storytelling with bereaved children. Webb (2000) discusses play therapy as a medium of support for bereaved children. Doka (2000) discusses the use of ritual in supporting bereaved children and adolescents. Another form of support is through group interaction. Dane (2002) and Schuurman (2000) both provide information on how to support bereaved children within a group context. What is essential no matter what form of support is used is that space be provided for revealing the experiences of loss for bereaved children.

Practitioners could also encourage conversation between parents and children as well. The themes found in this study could be shared with parents and children not as generalizations or norms but as a starting place for conversation (see Appendix G, p.112-113 for further practice ideas). How these four children experienced loss following the death of a significant adult could be shared with the parent and child and be followed by the question "what is your experience"? Such an opening creates opportunity for the

sharing of experiences between parent and child that can be helpful to both in understanding one another's meaning of the experience. Consider also, a child speaking of cherished memories being maintained through being with others, just as one of the participants of this study, Sean, shared how being with his grandmother helped him to remember his grandfather. "Well sometimes he would come to my hockey games and now grandma does so it's kind of like he's there too. It's ... like he's always there with her, like he would always be, like when he was alive ... sitting there in the background ..." Such information is important for parents to have. Knowing this, parents can help ensure that opportunities to be with the other grandparent continue.

Limitations of the research

While the findings contribute to knowledge generation of the experience of loss for bereaved children following the death of a significant adult, there are also limitations to this study. One such limitation is that all of the participants in this study represented white middle class Canadian culture so there is no information on how other cultural beliefs or socio-economic status shape bereaved children's experience of loss following the death of a grandparent. There was not a clear identification with a particular religious faith by any of the participants in this study so it is not known whether such a faith influenced the meaning of their experience of loss following the death of a significant adult or not. Also unknown was how the parents had experienced the death of their parent and ways it may have influenced how the children experienced the loss of their grandparent. It is not known whether the children had previous negative experiences of drawing a picture about their loss experience through other settings and this inhibited them from participating in such a fashion in this study. Baumann (1994) noted in his own

study on women and children with no place of their own, “With supportive others, young children joyfully reveal themselves through art, but they retreat into isolation and non-cooperation if too accurate a representation of reality is expected in their art” (p.167). Perhaps the children felt uncomfortable with the thought of having to draw a picture that would be a representation of their loss experience. A final limitation is that while being a palliative care counsellor for thirteen years certainly had its assets in carrying out this research, I also felt it brought detriments at times as well. I found this to be true particularly in doing the analysis process for the first objective regarding meaning. I realized I had my own biases based on both practice and personal experience of what the meaning of loss was and found those biases initially interfered with my ability to stay focused on what the four participants had revealed as their experiences.

Directions for further research

In accordance with Burns’ (1988) standards of rigor, the final dimension is that the findings of the study also need to guide future development of studies. This research has opened the door for further qualitative research with bereaved children as participants. It has provided the opportunity to describe the experience of loss for four bereaved children who have experienced the death of a grandparent. It would be important to learn about the experience of loss for bereaved children who have experienced the death of a parent or sibling. What are the similarities and differences, if any, between these types of death and the experience of loss for bereaved children? All the participants in this study experienced an expected death, i.e. the person who died had a terminal diagnosis. It would be helpful to learn more about the experience of loss for bereaved children who have experienced the death of a significant adult through sudden

death, through suicide and through homicide. It would also be helpful to have more knowledge of how family units experience loss following the death of a significant adult. It would also be helpful to have a greater understanding of if or how violence on television impacts children's experience of the loss of a significant adult.

Some of the participants spoke of what it was like for them while their grandparent was ill. Jane shares, "I didn't want him to be sick cause mommy and daddy said that he was going to die this time cause they thought that they had took out all the cancer and things but they hadn't and they couldn't fix him." A study exploring the experience of loss for children during illness of someone significant is likely important to do. Two of the participants in this study experienced multiple losses. Sean describes a "domino affect" of multiple loss, "... the domino thing is kind of like you are getting squished in the middle of it. You just don't feel good at all ... all these people dying." It would be important to learn more about the "domino affect" of multiple loss experiences for bereaved children. It would also be important to learn more about how children experience their own dying as it is a fear that may come up for children when they experience multiple loss.

Further research could also be conducted on any one of the themes identified in the findings of this current research study. For example, an in-depth inquiry could be made on anguish through separation, or relationships unfolding or perhaps the experience of being watched over. A final possibility to offer would be to explore the concept of changing self that is reflected in the literature on the grief process and find out if or how bereaved children experience that phenomenon.

Conclusion.

The experience of loss is an intensely personal experience and working on this study has reflected that same intensity at times for me. I became committed to the work of this study when, as a graduate student, I began searching for research on children and grief to complete some course assignments and became alarmed at how little research was available on this important experience for children. I had based my practice on available information about children and grief always assuming that somewhere along the line it had been based in research as well. I was shocked to find out that was not the case. This is not to say that practice information is not valid, for indeed it offers very valuable information on how to support bereaved children. However, I found that I personally could not shake the question, "how do we know if we haven't asked?" I needed to know that someone had taken the time and put forward the consideration to ask children directly about their experiences of loss. I wanted to know that bereaved children's voices were reflected in the research literature on this topic. I needed to know that someone would not just ask the question but would then find a way to relay the information to others who are also concerned about the experiences and needs of bereaved children. Like myself, each of the families, parents and children alike agreed to participate in this study because they too wanted to contribute knowledge generation about children's experience of loss in the hopes of helping other children and families who experience the death of someone they care about.

The findings of this study are not viewed as a conclusion to the research process but rather as the opening of the process. It is hoped that the findings of this study offer insight and appreciation for bereaved children's experiences of loss in addition to new knowledge regarding the time less experience of loss. It is hoped that the findings of this

research offer further insights into the theoretical perspective of human becoming and how it relates to research and practice. Finally, it is hoped that this research opens further doors for people to do qualitative research which includes children in general and particularly that which includes children in the area of loss through death. It is fitting that this study conclude with the words of the participants as they describe their experience of the loss of their grandparent:

From Holly, "Kinda lonely ... my grandma, she used to live downstairs and whenever I came downstairs it would always be a big deal and she would always say "hi" but now ... all we have is a student who lives downstairs ... and ... it's just lonely, it's boring."

From Sean, "It's kind of like ... when I go there after he died ... I expected him to be there sitting down in his chair. Say "how's it going" and stuff but when he's not there it just ... you feel empty inside."

From Jane, "It's been very sad." That he was my only grandpa left and I didn't want him to die."

Finally, from Bobby, "Well, it kinda does make me a little sad but then you just get that warm spot ..." "It's just a good feeling".

References

- Baumann, S.L. (1994). No place of their own: An exploratory study. *Nursing Science Quarterly* 7:4, winter 162-169.
- Baumann, S.L. (1996). Feeling uncomfortable: Children in families with no place of their own. *Nursing Science Quarterly* 9:4, winter 152-159.
- Baumann, S.L. (1997). Qualitative research with children as participants. *Nursing Science Quarterly* 10:2, summer 68-69.
- Baumann, S.L. (1999) Art as a path of inquiry. *Nursing Science Quarterly* 12:2, April 106-110.
- Baumann, S.L. (2001). Human becoming practice with children. *Nursing Science Quarterly* 14:2, April 120-125.
- Burns, N. (1988) Standards for qualitative research. *Nursing Science Quarterly* 2, 44-52.
- Butchko Kerr, R. (1994). Meanings adult daughters attach to a parent's death. *Western journal of nursing research* 16:4, 347-365.
- Cairns, M., Thompson, M, & Wainwright, W. (2003). *Transitions in dying & bereavement: A psychosocial guide for hospice and palliative care*. Baltimore: Health professions press.
- Carson, M.G. & Mitchell, G.J. (1998). The experience of living with persistent pain. *Journal of advanced nursing*, 28:6, 1242-1248.
- Cody, W.K. (1995). The meaning of grieving for families living with AIDS. *Nursing Science quarterly* 8:3, fall 104-114.
- Cody, W.K. (1991). Grieving a personal loss. *Nursing Science Quarterly* 4:2, summer 61-68.
- Dane, B.O. (2002). Bereavement groups for children: Families with HIV/AIDS. In N.B. Webb (Ed.), *Helping bereaved children: a handbook for practitioners 2nd edition*. (265-296). New York: The Guilford Press.
- Dietrich, P.J, McWilliam, C.L., Ralyear, S.F.& Schweitzer, A.T. (1999). Mother loss: Recreating relationship and meaning. *Canadian journal of nursing research* 31:2, 77-101.

- Doka, K.J. (2000). Using ritual with children and adolescents. In K.J. Doka (Ed.), *Living with grief: Children, adolescents, and loss*. (153-159). Hospice foundation of America.
- Eder, C. & Corsaro, W. (1999). Ethnographic studies of children and youth. *Journal of Contemporary Ethnography*, Oct.99 28:5, 520-32.
- Ellis, J.R. & Stump, J.E. (2000). Parent's perceptions of their children's death concept. *Death Studies* 24 65-70.
- Ericksen, J.R. & Henderson, A.D. (1992). Witnessing family violence: The children's experience. *Journal of Advanced Nursing* 17 1200-1209.
- Fleitas, J. (1998). Spinning tales from the World Wide Web: Qualitative research in an electronic environment. *Qualitative Health Research* Mar98, 8:2 283-293.
- Gall, M.D., Borg, W.R., & Gall, J.P. (1996). *Education Research: An introduction, 6th edition*. New York: Longman Publishers USA.
- Galloway, S. (1990). Young adults' reactions to the death of a parent. *Oncology Nursing Forum* 17:6, 899-904.
- Garbarino, J. & Stott, F. (1989). *What children can tell us*. San Francisco: Jossey-Bass Publishers.
- Goodman, R.F. (2002). Art as a component of grief work with children. In N.B. Webb (Ed.), *Helping bereaved children: A handbook for practitioners 2nd edition*. (297-322). New York: The Guilford Press.
- Haine, R.A., Ayers, T.S., Sandler, I.N., Wolchik, S.A. & Weyer, J.L. (2003). Locus of control and self-esteem as stress-moderators or stress-mediators in parentally bereaved children. *Death Studies*, 27 619-640.
- Hurd, R. (1999). Adults view their childhood bereavement experiences. *Death Studies* 23 17-41.
- Hutchings, D. (2002). Parallels in practice: Palliative nursing practice and Parse's theory of human becoming. *American journal of hospice & palliative care*, 19:6, November/December, 408-414.
- Hyslop-Christ, G. (2000). *Healing children's grief: Surviving a parent's death from cancer*. New York: Oxford University Press.
- Jenish, D. & DeMont, J. (1992). Prime-Time Violence. *Maclean's* 105,49 40-44.

- Jonas, C.M. (1992). The meaning of being an elder in Nepal. *Nursing Science Quarterly* 5:4 Winter 171-175.
- Knapp, N.F. (1997). Interviewing Joshua: On the importance of leaving room for serendipity. *Qualitative inquiry* Sep.97, 3:3 326-343.
- Kvale, S. (1996) *Inter Views: An introduction to qualitative research interviewing*. Thousand Oaks, Ca: Sage Publications, Inc.
- Lepine, S. & Smolla, N. (2000). Ethical issues concerning participants in community surveys of child and adolescent mental disorders *Canadian Journal of Psychiatry*, 45:1 48-54.
- Nagy, M. (1948). In R. Lonetto (Ed). *Children's conceptions of death*. New York: Springer Publishing.
- Northrup, D.T. (2002). Time passing: A Parse research method study. *Nursing Science Quarterly*, 15, 4, October 318-326.
- Oesterheld, J.R., Fogas, B., & Rutten, S. (1998) Ethical standards for research on children. *Journal of American Academy of Child and Adolescent Psychiatry* July 98, 37:7 684-685.
- Orbach, I., Weiner, M., Har-Even, D. & Esherl, Y. (1994). Children's perception of death and interpersonal closeness to the dead person. *Omega* 30:1 1-12.
- O'Toole, D.R. (2002). Storytelling with bereaved children. In N.B. Webb (Ed.), *Helping bereaved children: A handbook for practitioners 2nd edition*. (323-345). New York: The Guilford Press.
- Parse, R.R. (1981). *Man-living-health: A theory of nursing*. New York: John Wiley.
- Parse, R. R., Coyne, A.B. & Smith, M.J. (1985). *Nursing research: Qualitative methods*. New York: Brady Communications.
- Parse, R.R. (1992). Human becoming: Parse's theory of nursing. *Nursing Science Quarterly* 5:1 spring 35-42.
- Parse, R.R. (1998). *The human becoming school of thought: A perspective for nurses and other health professionals*. Thousand Oaks, Ca: Sage Publications.
- Parse, R.R. (2001). *Qualitative inquiry: The path of sciencing*. Sudbury, MA: Jones & Bartlett.
- Peled, E. (1998). The experience of living with violence for preadolescent children of battered women. *Youth & Society* Jun98, 29:4 395-431.

- Petersen, S. & Ecchevaria Rafuls, S. (1998). Receiving the scepter: The generational transition and impact of parent death on adults. *Death Studies* 22, 493-524.
- Pilkington, F.B. (1993). The lived experience of grieving the loss of an important other. *Nursing Science Quarterly* 6:3, Fall 130-139.
- Powell, M.P. (1994). Issues related to research with children: What counseling psychologists need to know. *Counseling Psychologist* Jul94, 22:3 444-454.
- Rando, T.A. (1984). *Grief, dying, and death: Clinical interventions for caregivers*. Illinois: Research Press Company.
- Rogers, M.E. (1970). *An introduction to the theoretical basis of nursing*. Philadelphia: Davis.
- Rosenblatt, P.C. (1995). Ethics of qualitative interviewing with grieving families. *Death Studies*, 19 139-155.
- Rowling, L. (1999). Being in, being out, being with: Affect and the role of the qualitative researcher in loss and grief research. *Mortality* Jul99, 4:2 167-182.
- Schuurman, D.L. (2000). The use of groups with grieving children and adolescents. In K.J. Doka (Ed.), *Living with grief: Children, adolescents, and loss*. (165-177). Hospice foundation of America.
- Silverman, P.R. & Worden, J.W. (1992a). Children's reactions in the early months after the death of a parent. *American journal of orthopsychiatry* 62, 93-104.
- Silverman, P.R. & Worden, J.W. (1992b). Detachment revisited: The child's reconstruction of a dead parent. *American journal of orthopsychiatry* 62, 494-503.
- Silverman, P.R. (2000). *Never too young to know: Death in children's lives*. New York: Oxford Univeristy Press.
- Tammivaara, J. & Enright, D.S. (1986). On eliciting information: Dialogues with child informants. *Anthropology & Education Quarterly* 17 218-238.
- van Manen, M. (1998). *Researching lived experience: Human science for an action sensitive pedagogy*. London Ontario: The Althouse Press.
- Waters, E., Merrick, S., Treboux, D., Crowell, J. & Albersheim, L. (2000). Attachment security in infancy and early adulthood: A twenty-year longitudinal study. *Child Development* May/June2000, 71:3 684-689.

- Webb, N.B. (2000). Play therapy to help bereaved children. In K.J. Doka (Ed.), *Living with grief: Children, adolescents, and loss*. (139- 152). Hospice foundation of America.
- Webster's College Dictionary (1996). New York: Random House.
- Wolfelt, A.D. (1996). *Healing the bereaved child, grief gardening, growing through grief and other touchstones for caregivers*. Fort Collins, CO: Companion Press.
- Worden, J.W. (1991). *Grief counseling & grief therapy: A handbook for the mental health practitioner*. New York: Springer Publishing Company Inc.
- Worden, J.W. (1996). *Children and grief when a parent dies*. New York: The Guilford Press.
- Worden, J.W. Davies, B. & McCowan, D. (1999). Comparing parent loss with sibling loss. *Death Studies*, 23 1-15.
- Wright, K. and Flemons, D. (2002). Dying to know: Qualitative research with terminally ill persons and their families. *Death Studies*, 26:255-271.
- Yagla Mack, K. (2001). Childhood family disruptions and adult well-being: The differential effects of divorce and parental death. *Death studies*, 25 419-443.

Appendix A

Letter of invitation

Dear (family name),

My name is Allyson Whiteman and I am a graduate student currently completing my degree in Child and Youth Care at the University of Victoria. I am writing to you and your family today to invite you to consider having one or more of your children participate in a research study on children's experience of loss related to the death of a significant adult in their lives. I obtained your name from Victoria Hospice's bereavement data base as your family had been recipients of service from Victoria Hospice. I have worked as a counsellor for both adults and children at Victoria Hospice for the past 12 years and in returning to school I discovered what little research is available about children's loss of a significant adult. I want to change that and I am hoping that you and your family want to also. If you choose not to participate there will not be any consequence for that decision nor any need for explanation of your decision.

The study asks that your child participate in one interview (with an option of a second if he or she desires) with the researcher. The interviews will include your child either talking or representing their loss experiences through drawing pictures and then verbally telling me about their drawings. Your child's participation would be completely voluntary and he or she can withdraw from the research study at any point in time without any consequence or need for explanation. You also maintain the right to withdraw your child from participating in the study at any time. Confidentiality of your family will also be protected through the use of fictional names.

Your child's participation in this study has the potential to provide valuable information for other families, practitioners and researchers about the experience of loss for bereaved children following the death of someone close to them. This information will go on to help people charged with the care of bereaved children understand what that experience is like for children.

If you would like to discuss this study in more detail, please leave a message at Victoria Hospice with Jane at (370-8868) and I will be in touch with you promptly. You are also invited to speak with my faculty supervisor at the University of Victoria Dr. Daniel Scott (472-4770) or Dr. Howard Brunt, Associate Vice-President Research at the University of Victoria (472-4632).

Thank you for your consideration of this matter.

Sincerely,

Allyson Whiteman

Appendix B

Children and loss: a descriptive exploratory study of bereaved children's experience of loss following the death of a significant adult

Your child is being invited to participate in a study entitled Children and loss: a descriptive exploratory study of bereaved children's experience of loss following the death of a significant adult that is being conducted by Allyson Whiteman. Allyson Whiteman is a graduate student in the department of Child and Youth Care at the University of Victoria and you may contact her at 250-384-1792 if you have further questions. As a graduate student, I am required to conduct research as part of the requirements for a Masters of Arts degree in Child and Youth Care. It is being conducted under the supervision of Dr. Daniel Scott. You may contact my supervisor at 250-472-4770 and dgscott@uvic.ca. Contemporary literature indicates that practitioners, researchers and adults alike do not have an adequate understanding of children's experiences of the death of a significant adult from the bereaved child's own perspective. This research study is a start in addressing the gap.

You have agreed to your child's voluntary participation in this study. Your child's participation will involve one interview (with the option of a second if he or she desires) of approximately 30 to 45 minutes in length. Your child is welcome to shorten or lengthen that time frame if he or she desires. The interview will include the option of either talking about or drawing about his or her experience of loss following the death of a significant adult. If your child decides to draw the experience, then he or she will then be asked to describe the drawing to the researcher. The interview is semi-structured giving your child the freedom to say and not say what he or she wishes. With the permission of your child and yourself, the interviews will be audio-taped. The location for the interviews is a play therapy studio at 120 St. Andrews St. Victoria, B.C. The decision for this location is that it is a child friendly environment which also has a waiting area for parents making it convenient for the family. The location will also ensure confidentiality of the interviews as your child will be in a location which provides privacy. Participation in this study may cause some inconvenience to you and your family, including time. I am willing to be flexible in terms of scheduling the interviews in such a fashion that they provide minimal disruption to your family.

There is a potential risk of emotional upset to your child by participating in this research. To prevent or deal with this potential risk, the following steps will be taken. A 30- minute observation period of the child by the researcher will follow each interview. In addition, the researcher will place a call to you and your child one day and one week following the interview for the purpose of checking on possible reactions (both positive and negative) that the child may have experienced from participating in the interview. Parents and children will be encouraged to phone the researcher before the proposed time frames if any problems or concerns arise. Staff at Victoria Hospice have been retained to provide individual counselling for any child or family member who may request it due to

emotional upset arising from participation in the research study. The parents and children will also be supplied with a list of community resources available that provide group support for bereaved children if that is the preferred format of support by the parent and/or child.

In addition to the potential risk, there are also potential benefits to your child's participation in this research. These include research that indicates that some people find it helpful to tell the story of their loss in the research interview format. In addition, your child's participation in this study has the potential to provide valuable information for other families, practitioners and researchers about the experience of loss for bereaved children following the death of someone close to them.

Your child's participation in this research must be completely voluntary. If you do decide to give consent for your child to participate, please understand that your child has the right to withdraw from the study at any time and without any consequences or need for explanation. If your child does decide to withdraw, I will ask for permission from both you and your child to include any data previously gathered in the research study. Your or your child's refusal to include this data will be accepted without any consequences or need for explanation.

In order to address the issue of power that inherently exists between adult and child, the interviews will be conducted following guidelines laid out by researchers who have previously conducted qualitative research with children. These researchers recommend resolving the power differential through asking open-ended questions and following the child's lead. It is also recommended to have drawing materials present during the interview process. Drawing materials help the child create a natural distance between him or herself and the topic.

In terms of protecting your family's anonymity the identity of the participants will be protected within any written reports through the use of fictional names. Any third party identities will also be protected through the use of fictional names. In order to protect the confidentiality of your child, specific information about the child's interviews will not be shared with you unless risk of harm to your child is revealed. The data which will use fictional names, will be kept in a locked, secured filing cabinet and will be viewed by the researcher, and where appropriate her supervisor and other committee members only. The data provided in your child's interview will be used in my Master's thesis to bring me to the completion of a Master's of Arts degree in Child and Youth Care. The findings may also be published in journals and presented at workshops so that the important information found in this study can be passed along to other practitioners working with bereaved children. Data from this study will be disposed of by erasure of the audio-taped interviews and shredding of the transcriptions. With permission from your child, his or her drawing or a copy of it may be kept for presentation purposes but will have any identifying information removed from it.

In addition to being able to contact the researcher [and, if applicable, the supervisor] at the above phone numbers, you may verify the ethical approval of this study, or raise any

concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria (250-472-4362).

I want to thank you for agreeing to your child's participation in this important research investigation. I would again like to assure you that the well being of your child and family will be kept in mind at all times.

Your signature below indicates that you understand the above conditions of your child's participation in this study and that you have had the opportunity to have your questions answered by the researcher. Your signature below also indicates your consent to having your child's interviews audio-taped.

Name of Participant

Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher

Appendix C

Child consent form

Allyson Whiteman told me that she would like me to talk about or draw my experiences of loss since _____ died

1. I will talk about or draw pictures of what it has been like for me since _____ died.
2. I understand my conversations with Allyson will be tape-recorded if I say that is o.k.
3. If I draw, Allyson will ask to keep those pictures or a copy of them.
4. I will let Allyson know if I feel uncomfortable during our talks. I will let her know if I do not want to talk about something.
5. I can stop drawing or talking and not be part of the study whenever I feel like it. I understand Allyson or my parents will not be upset if I want to stop.
6. I will let Allyson or my parent know that I want to stop.
7. The drawings and tapes will be used to write a story that other people can read.
8. Allyson will make sure that no one knows that I was one of the children in this study because she will use pretend names.

I am willing to talk about or draw pictures about what it has been like since _____ died with Allyson Whiteman. I know Allyson is going to tape our talks. I know she is going to use the drawings and tapes to write a story for other people to read to help people understand what it is like for children when someone close to them has died.

_____ (Date)

_____ (Signature)

_____ (Researcher Signature)

Appendix D

Guiding principles for the interview process:

- Rapport building will have begun with the child in the face-to-face meeting in which the child signed the consent to participate form.
- The interview(s) will be conducted in a child friendly environment that also addresses the child's rights to privacy during the interview(s).
- The child will be offered the option to talk about or draw his or her experiences of loss following the death of a significant adult.
- Open- ended questions that follow the lead of the child will be used in the interview(s). This is done to support the child in having a sense of control over the interview(s) process and is also true to the methodology for data gathering purposes.
- At the start of each interview (if there is more than one) the child will be reminded of his or her right to withdraw from the study. At this time he or she will also be reminded that there will be no punishment for doing so.
- If a child exhibits behaviors of agitation, and disconnection from the researcher, the researcher will check-in with the child with the question "what's happening right now?" and if appropriate, the child will be reminded of his or her right to withdraw from the study.
- A 30- minute observation will follow the end of the interview. This will consist of the researcher staying with the child and providing some winding down activity, for example, a short card game, with the child.
- A follow up phone call by the researcher to the parent(s) and child will be made one day and one week following the interview(s) to check on possible reactions (both positive and negative) that the child may have experienced from participating in the research.

Objective 1: To describe the meaning related to bereaved children's experience of loss following the death of a significant adult.

- a. What has it been like for you since ____ died?

Objective 2: To describe how relationships unfold for bereaved children experiencing loss related to the death of a significant adult.

- a. What is important to you about the people, things or activities you are speaking or drawing about?

Objective 3: To describe children's changing perspectives on their desires, hopes and dreams following the death of a significant adult.

- a. How would you like things to be different?

Appendix E

Demographics Collection Sheet

Child's age and date of birth:

Gender:

Relationship of deceased:

Time elapsed since death:

Cause of death

Nature of existing relationship with another research participant (if applicable)

Previous losses

Current support system

Appendix F

Telephone Script

Hello;

My name is Allyson Whiteman. I am a graduate student in the department of Child and Youth Care at the University of Victoria. I am calling today to follow up on a letter that your family received inviting any child living in your home between the ages of 8-10 years of age to participate in a research study I am conducting on bereaved children's experience of loss following the death of a significant adult. The purpose of my phone call today is to introduce myself and to provide you and your family with the opportunity to ask questions and gain further information about the study. I also want to learn whether or not your family may be interested in participating in this research. If you decide that you are not interested in your child participating in this research, there will be no consequences resulting from your decision and no need for explanation for your decision.

I would like to share with you that I have 12 years experience as a counsellor with Victoria Hospice and have extensive practice working with children in that setting through providing individual and group support. Great care and attention has been given to the design of this research so that it is responsible to children of this age around a topic that is sensitive. Ways that this has been taken into consideration are through such things as your child having the option to draw or talk about their experience, your child need only participate in a single interview, your child has the right to stop participating without consequence at any time, also counselling support has been arranged through Victoria Hospice should your child or you feel a need for it. I also have available other community resources for bereaved children if they might interest you as well. Finally, your family's anonymity will be maintained at all times through the use of fictional names on any data arising from your child's interview.

I am wondering if there is any additional information you would like to have regarding this important research?

Do you have any further concerns regarding your child participating in such a study that you would like to explore further with me today?

If you are agreeable, I would like to schedule a face-to-face meeting at your convenience with you and your child to further discuss your child's participation in this research study. This meeting will provide you and your child the opportunity to ask me any questions about the research. At the meeting I would also like to discuss the possibility of consent to participate in the study with both you and your child.

Thank you so much for your consideration of this research study on children's experience of loss following the death of a significant adult.

Appendix G

Suggestions for creating space for children to reveal their loss experiences.

Before proceeding with providing some suggestions on how to invite children's expression of loss experiences it is important that I identify assumptions I carry in supporting bereaved children. My first assumption is that people are the experts of their own lives and it is through understanding their perspective that we are able to provide appropriate support. My second assumption is that each person has unique and individual experiences that shape their world. Therefore, the suggestions offered are presented as ideas and not specific guidelines for parents or practitioners to follow when supporting bereaved children.

The format of this handout is organized by concepts found in the themes of this research study. An opening question is suggested for each concept. It is followed by a quote from one of the child participants in this study as an example of a response to the question. Following the quote, further follow up questions are provided as ideas on how to explore the experience further with the child.

First, creating space involves taking time out of schedules for conversations or responding in the moment to opportunities that arise from events happening around or from the child him or herself. Following are some suggestions of how to create space for open exploration of a child's experiences:

1. Let the child know that what he has to say is important to you.
2. Listen attentively to what the child says.
3. Be willing to explore further what it is you do not understand by asking the child open ended questions.
4. Be respectful of what you hear. Remember the child is talking about her experience. It will be different from your own. This is not cause for alarm or judgment.
5. Share appreciation for what the child has shared with you.

Theme suggestions

Description of loss experience:

What has it been like for you since (person's name) died?

Jane: "It's been really sad."

What has been sad for you?

Jane: "That he was my only grandpa left and I didn't want him to die."

Tell me about not wanting him to die Jane, what was that like for you?

Memories of the person who died:

What is important to you about (person's name)?

Holly: "That she's not one of those grandma's that just say 'do this right now because I don't have any time and she show's you how to do the thing you don't know how to do and doesn't yell at you if you've done something wrong."

It sounds like you enjoyed learning with Grandma. What are some of the things she taught you?

How do you use the things you have learned from grandma now?

Hopes and desires:

How would you like things to be different?

Bobby: "I do hope he would still be around."

What would you do with grandpa if he was still around?

What would it mean to you to do these activities with grandpa again?

Watching over:

How do you stay connected with (person's name)?

Sean: "It feels as if he's there for that bit and that he's watching me or something."

How is it for you to have grandpa watching you?

When do you experience grandpa watching you?

Are there other times you experience grandpa watching you?