Living with Uncertainty:
The Experiences of Parents and Children When a Parent is
Living with, and Dying from, Advanced Cancer

by

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A thesis submitted in conformity with the requirements
for the degree of Doctor of Philosophy
Factor-Inwentash Faculty of Social Work
University of Toronto

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Doctor of Philosophy, 2017
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Abstract

Advanced cancer and its progression and treatment deeply affect members of a family, especially the children. The limited research contends that the complexities of advanced cancer and the anticipated loss of a parent result in greater psychosocial vulnerability for children, compromising their wellbeing (Beale et al., 2004; Bugge et al., 2008; Christ, 2000).

Conducted at the Princess Margaret Cancer Centre, University Health Network, Toronto, Ontario, the purpose of this interpretive research was to investigate the experiences of parents and children six to eighteen years coping with a parent living with, and dying from, advanced cancer. This study focused on the meaning children and parents ascribe to this time of uncertainty, in addition to aspects such as emotional security, and the role of parents in understanding, and ameliorating, potential effects to children. Seven families participated in the study (seven parents with advanced cancer, four children, and four well parents).

A review of the existent literature was presented thematically, and demonstrated critical gaps and meagreness of the research. The theoretical framework encompassed social constructivism and sociocultural theory, in addition to the relational theories of attachment and intersubjectivity. Aspects of neurobiology underpinned the framework. Each facet of the framework was situated within the context of children and parents coping with advanced cancer and anticipatory loss. A theoretical model depicts this framework.
Hermeneutic interpretive phenomenology was the methodology incorporated in this study. The primary method of data collection was semi-structured interviews with children and parents separately. Interpretative Phenomenological Analysis (Smith et al., 2009) guided the data analysis and interpretation. Results of the study are presented as a discussion of the themes, illustrated in an accompanying map. A review of the findings in relation to the research questions, the empirical literature, and theoretical framework reveals potential contributions of this research. This study concludes with implications for scholarly knowledge, social policy, social work education and practice, and recommendations for future research. Results of this research will advance the understanding of the experiences of parents and children, inform social work education and practice, and facilitate the development of interventions promoting positive outcomes for children and families.
Acknowledgements

Courage doesn't always roar.
Sometimes courage is the quiet voice at the end of the day saying,
"I will try again tomorrow."
(Radmacher)

In penning the Acknowledgements for my doctoral thesis, it means that my doctoral journey has come to an end – I have arrived. It has been a journey filled with validation, wonder, but also ongoing courage to ‘try again tomorrow’ while living with challenges and adversity. During this journey, I have had the good fortune to receive support from many individuals, each of whom holds a special place for me in making this thesis possible. It is my pleasure to thank all of you.

I owe my deepest and heartfelt gratitude to my supervisor, Dr. Faye Mishna, Dean, for her invaluable and unwavering support, guidance, wisdom, and encouragement throughout this process. It has been truly an honor to have such a dedicated supervisor and mentor.

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My thanks also go to Tanya Hyland, Ellie Goldenberg, and the dedicated electronic note takers in Accessibility Services at the University of Toronto who helped with the doctoral process and my ongoing challenges.

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Personally I would not be at the end of my doctoral journey without the unending support of my ‘family of friends’ who believed in me, kept me going, and cheered me on with encouraging words, prayers, and unconditional acceptance.

It is to my father, my son, and Maggie, my service dog, that I dedicate this Doctoral Thesis. My father taught me about living well, the courage to persevere no matter what the obstacles, and dying with grace. I am the person I am today because of you, Dad. My son, Joseph, has been the wind beneath my wings, being with me every step of the way, and helping me to continue putting one foot in front of the other.
A special place in this process is held for Maggie my trusted companion, who has been by my side for more than 10 years with tireless dedication and unending affection, and for whom retirement awaits.

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Chapter One
Introduction

“Both my parents make me whole. Now that my mom is dying I can’t see how that is going to ever be the same, half of my world will be gone. I am so close to my dad but he just isn’t my mom!”

The above represents the ‘voice’ of a child whose mother’s death from cancer was imminent. The depth of her sense of loss is readily apparent. Coping with a parent’s terminal illness, such as advanced cancer, represents a time of considerable uncertainty and distress for family members, especially children. Melcher, Sandell, and Henriksson indicated, “A progressive incurable illness in a parent can have a crucial impact on the structure and functioning of their family, and perhaps more so on their children” (2015, p. 1595). Issues such as treatment and its side effects, frequent absences of one or both parents, and caregiver burden often confuse children and reverberate throughout the family. Additionally, the progression of a parent’s cancer may heighten the child’s fear of life without their parent.

Typically in such crises, a child’s parent, or attachment figure, represents someone on whom the child can rely for support and guidance, an emotional anchor. When a child’s parent is terminally ill, the child faces not only the loss of a parent, but also the loss of this critical emotional bond. This compounds a child’s confusion and distress. Often, the well parent or caregiver may experience his/her own emotional turmoil, potentially affecting parental efficacy and emotional availability to the child. Parents and professionals struggle with how to support children. Research indicates that society tends to shy away from this traumatic time as it can invoke discomfort (Goodman, 2001; Huff et al., 2006; Kennedy & Lloyd-Williams, 2009a; Turner, 2004; Webb, 2005). Jenkinson indicated, “Society has an impoverished sense of what children are capable of which results in a tendency to protect children against what adults fear most” (2004, p. 21). Zaider, Salley, Terry, and Davidovits also noted, “In the advanced stages of
illness, families with dependent children experience disruption across all dimensions of family life. The need for family support during palliative care is well recognized, yet little is understood about how parents and their children navigate these difficult circumstances” (2015, p. 52).

Furthermore, the loss of a parent may result in significant changes for a child with regard to social location and positionality. The death of a parent, for example, changes a parent/son or daughter relationship forever; something the child will never again experience in the tangible sense (Fearnley, 2012; Goodman, 2001; Webb 2005). Such loss has the potential to create a sense of difference or ‘otherness’ for the child with respect to peers who have not experienced the death of a parent. The changes resulting from the anticipated loss represent considerable uncertainty for children (Beale, Sivesind & Bruera, 2004; Bugge, Helseth & Darbyshire, 2008; Christ, 2000; Kennedy & Lloyd-Williams, 2009a). Kiely, Tattersall, and Stockler conceptualized the tenuousness of the dying time as, “a certain death at an uncertain time” (2010, p. 2802).

Statement of the Problem

As Lewis (1990) indicated “cancer invades the family; not just the diagnosed patient’s body” (p. 752). Children often struggle when their parent is living with, and dying from, advanced cancer (as discussed in Chapter Two). Parents may find it difficult to respond to, or may not recognize, their children’s struggles. Moreover, professionals such as social workers are often at a loss of how to support children experiencing distress and anticipatory loss (Csikai & Raymer, 2005; Huff et al., 2006; Mullin & Canning, 2006; Webb, 2007). There has been little research, however, on this compelling issue. The dearth in the literature raises the need for research incorporating the voices of children and their parents or caregivers to fully comprehend the complexities of advanced terminal cancer faced by families. Zaider et al. made a case for such research, stating “The study of parental cancer has predominantly focused on the early
stages of disease and its impact on children and adolescents, with less known about how families with minor children prepare for parental loss” (2015, p. 53).

For the purposes of this research and dissertation, “family” will be viewed in accordance with the definition outlined by The Vanier Institute of the Family (2016, para 2):

Any combination of two or more persons who are bound together over time by ties of mutual consent, birth and/or adoption or placement and who, together, assume responsibilities for variant combinations of some of the following:

- Physical maintenance and care of group members
- Addition of new members through procreation or adoption
- Socialization of children
- Social control of members
- Production, consumption, distribution of goods and services
- Affective nurturance – love

This definition is inclusive of the increasing diversity in family structure. Moreover, as it is important to consider that the adult supporting the dying parent and child may not be a parent, the use of the term caregiver has been included when discussing the well parent.

Background and Context for the Study

Cancer impacts the lives of many. The Canadian Cancer Society (CCS) indicated that in 2015 an average of 539 Canadians would be diagnosed with cancer daily, while 214 Canadians would die from cancer. Specifically, it was estimated that every hour nine people would die of cancer in Canada in 2015 (CCS, 2015, p. 38). Although the incidence of cancer and mortality rates are higher among older people, the Canadian Cancer Society’s Steering Committee reported, “30% of new cancer cases and 17% of cancer deaths will occur in young and middle-age adults aged 20 to 59, in the critical period when they are raising their families” (as cited in Rainville et al., 2012, p. 520).
The potential years of life lost (PYLL) represents an alternate measure to death rates. PYLL takes into account average life expectancy and gives more weight to deaths among younger people. From this, cancer is the leading cause of premature death and potential years of life lost in Canada (CCS, 2015, p. 10). This is significant for children and families who experience life altering circumstances when a parent lives with, and dies from, cancer. Sheehan and Draucker noted that, “children must first cope with the illness of the parent, and then face life without him or her” (2011, p. 1108).

**Advanced Cancer**

Cancer and its treatment can have profound and long-lasting effects on many aspects of an individual’s life and the lives of family members. This is particularly true with advanced cancer. The National Cancer Institute (NCI) defines advanced cancer as “cancer that has spread to other places in the body and usually cannot be cured or controlled with treatment” (NCI Dictionary of Cancer Terms, 2016, para 1). Incurable, terminal, Stage IV, or metastatic disease are terms equated with advanced cancer. Maintaining or improving quality of life and extending life as long as possible are considered the primary aims for the treatment of advanced cancer. Fineberg et al. reiterated this noting, “for patients with incurable illnesses, the goals of care may shift from aims for ‘cure’ to alleviation of suffering, support for the best quality of life until death occurs, and provision of comfort at the end of life” (2007, p. S29).

**Cancer Health Disparities**

An important area of cancer research centers upon health disparities which create a disproportionate burden of disease on individuals or populations, primarily those who are marginalized and disadvantaged economically or socially. The National Cancer Institute (NCI) describes cancer health disparities as:
Adverse differences in cancer incidence (new cases), cancer prevalence (all existing cases), cancer death (mortality), cancer survivorship, and burden of cancer or related health conditions that exist among specific population groups in the United States. These population groups may be characterized by age, disability, education, ethnicity, gender, geographic location, income, or race. People who are poor, lack health insurance, and are medically underserved (have limited or no access to effective health care)—regardless of ethnic and racial background—often bear a greater burden of disease than the general population. (2008, para. 1)

All aspects of the cancer trajectory such as incidence, survival, and mortality are affected by these disparities. They can contribute to a diagnosis of advanced or terminal cancer for those who are marginalized (Barton-Burke, Smith, Frain, & Loggins, 2010; Nedjat-Haiem, Carrion, Ell, & Palinkas, 2012; Nishri, Sheppard, Withrow, & Marrett, 2014). These disparities result from a complex interactions between the factors outlined in the following table:

<table>
<thead>
<tr>
<th>Cancer Health Disparities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual factors</td>
</tr>
<tr>
<td>• genetic endowment, perceptions, beliefs, health behaviors, culture, diet</td>
</tr>
<tr>
<td>Social and economic factors</td>
</tr>
<tr>
<td>• racism, discrimination, social marginalization, education levels, and socioeconomic status (SES)</td>
</tr>
<tr>
<td>Environmental factors</td>
</tr>
<tr>
<td>• neighborhood conditions, exposure to toxic environments</td>
</tr>
<tr>
<td>Availability of quality health care</td>
</tr>
<tr>
<td>• access to health care, utilization of care, and provision of care</td>
</tr>
</tbody>
</table>

(Barton-Burke et al., 2010, p. 157)

**Financial burden of cancer.** In his discussion paper, *Poverty, Culture, and Social Injustice Determinants of Cancer Disparities* (2004), Freeman highlighted research which determined that poverty, culture, and social injustice are considered to be the three main social disparities having the greatest effect on cancer outcomes. He further indicated that poverty had
the most deleterious effect, concluding that “poverty and cancer are, too often, a lethal combination” (p. 74). The Canadian Cancer Society captured the deleterious effect of the financial burden of cancer indicating:

Nine out of ten Canadian families touched by cancer report some form of financial challenge as incomes decline and household costs rise. For some, a cancer diagnosis begins a financial tailspin that pushes ordinary people over the edge resulting in debt, distress, bankruptcy and even a lifetime on social assistance. (2016, para. 1)

Much of the financial burden relates to treatment, especially the high cost of specific target drugs. Although insurance benefits ease some of the cost, many drugs are only partially covered or not covered at all. Additionally, not all Canadians have insurance benefits and extended costs are often not covered by a provincial health plan. Ip (2013) brought awareness to the high cost of cancer treatment stating, “According to the Canadian Cancer Society, about three-quarters of these drugs cost over $20,000 with a single course of treatment averaging at $65,000” (para. 2).

A significant decline in family income, in addition to high out of pocket expenses, can heighten this financial hardship. Hopkins, Goeree, and Longo (2010, p. 40) noted the results of a 2009 national survey, “91% of respondents with a diagnosis of cancer suffered significant loss of income coupled with increased personal expenses from travel, meals, parking, long distance phone calls, alternative or herbal treatments, drugs that may not be covered, new clothing due to drastic weight loss, and much more.” Financial toxicity or treatment-related toxicity are terms that characterize these out-of-pocket health care costs (Zafar & Abernethy, 2013).

The financial burden of cancer affects, and is affected by, race and socioeconomic status (SES). Barton-Burke et al. (2010) referred to a direct correlation between advanced cancer, insurance status, and Americans who are marginalized. The authors indicated that “minority
women diagnosed with advanced cancer are less likely to have health insurance and tend to have lower educational levels and lower incomes” (p. 160).

**Race and ethnicity.** Barton-Burke et al. (2010) equated cancer health disparities to euphemisms for racism and discrimination for vulnerable and high-risk populations (p. 158). Despite improvements in early detection, treatment, cancer care, and survival rates, “all segments of the population have not equally benefited and the burden of cancer is disproportionately borne by the socioeconomically disadvantaged and racial/ethnic minorities” (Tehranifar et al., 2009, p. 2701). The research related to race and ethnicity, cancer health disparities and advanced cancer documented the following significant differences in specific populations:

- African Americans have the highest death rate from all cancer sites combined and from malignancies of the lung and bronchus, colon and rectum, female breast, prostate, and cervix of all racial or ethnic groups in the United States (Ward et al., 2004, p. 80);

- There is a higher incidence of breast cancer in white women, however the mortality rates were higher among black women (Merkin, Stevenson, & Powe, 2002, p. 64);

- When poverty is controlled for, African American, American Indian/Alaskan Native, and Asian/Pacific Islander men and African American and American Indian/Alaskan Native women have lower five-year survival (Ward et al., 2004, p. 78);

- Black men have the highest prostate cancer incidence and mortality of any group (Gilligan, 2005, p. 49);

- Lung cancer incidence in the United States is highest among blacks who are diagnosed at younger ages with more advanced disease than other patients (Lin et al., 2014, p. 490);

- Chinese Americans experience the highest mortality rate for liver cancer, Filipinos have a higher incidence and mortality from thyroid cancer, and Vietnamese women have a two and a half times higher cervical cancer incidence rate. (Barton-Burke et al., 2010, p. 158).

With respect to advanced cancer, it is clear that minority groups do not have equal ground (Glanz, Croyle, Chollette, & Pinn, 2003). The research makes reference to reasons for the unequal burden of cancer related to race and ethnicity. The primary reason focused on lack of screening opportunities which can lead to later stage diagnoses with significantly poorer
prognoses. Additional reasons focus on treatment disparities, SES / poverty, lack of health insurance, language barriers, cultural differences, lack of culturally sensitive health care, and lower educational attainment (Barton-Burke et al., 2010; Nedjat-Haiem et al., 2012; Ward et al., 2004; Tehranifar et al., 2009).

Freeman discussed another reason stating “studies suggest that racial and ethnic bias on the part of medical care providers and possibly patient bias influence the quality of health care delivery. The level and extent of this problem are unknown” (2004, p. 76).

**First Nations, Inuit, and Métis in Ontario.** Not gaining equal ground describes the cancer burden and disparities experienced by First Nations, Métis and Inuit in Ontario. Cancer incidence, particularly advanced cancer, is increasing more rapidly and cancer survival is worse than other groups (Kewayosh et al., 2015; Marrett, & Chaudhry, 2003; Nishri et al., 2014; Sheppard et al., 2010).

An investigation of the incidence and survival rates for five major cancer types (breast, cervix, colorectal, lung and prostate) between First Nations peoples and other populations in Ontario from 1968-2001 was conducted by Nishri et al. (2014). Results confirmed “survival rates were poorer in the First Nations population compared to Ontarians with the difference exceeding 10% for every cancer” (p. 640). First Nations women were diagnosed with a later stage of breast cancer more often than non-First Nations women. Research conducted by Marrett, and Chaudhry (2003), Sheppard et al. (2010), and Kewayosh et al. (2015) reported similar conclusions.

Possible reasons for the results illuminate the unequal cancer burden. Kewayosh et al. (2015) argued that poorer medical care and limited access to medical care are associated with the social disparities of lower education, higher unemployment, lower median income, poor housing, geographic isolation, language barriers, and cultural differences. The authors also indicated that
there is often a delay in individuals from First Nations, Métis and Inuit populations in Ontario seeking health care until seriously ill. This is due to “a fear that the diagnosis may result in leaving the community for health care, and the possibility that the help received may not be culturally safe affecting follow up or continued health care” (2015, p. 35). Nishri et al. (2014) identified a lack of routine screening and comorbidity with other health concerns such as diabetes which contribute to late stage diagnoses and poorer outcomes.

**Summary.** Significant cancer health disparities create an unequal cancer burden experienced by many vulnerable Canadians, particularly those diagnosed with advanced cancer. The medical advances in cancer screening, treatment and outcomes are of benefit to some, not all. Ahmed and Shahid argued that “with the rising incidence of cancer and the increasing numbers of minorities and of social disparities in general, and without appropriate interventions, cancer care disparities will become only more pronounced” (2012, p. 376). The ramifications of cancer health disparities and the unequal burden to vulnerable populations can impact the circumstances with which individuals and families must cope.

Although the extant empirical literature focuses on cancer health disparities and advanced cancer, the research has not yet focused on the implications of these disparities for families coping with a parent living with, and dying from, advanced cancer. As such, this represents an important area for future research.

**Psychosocial Oncology and Palliative Care: Critical Social Issues**

Often seen as an emotionally charged experience, individuals living with, and dying from, advanced cancer must cope with ongoing distress. Aspects such as the side effects of treatment, worry for loved ones, and death anxiety heighten this distress. Supporting psychosocial needs is a significant part of promoting the quality of life of an individual living terminal cancer. As a key
facet of cancer care, psychosocial oncology is concerned with “the understanding and treatment of the social, psychological, emotional, spiritual, and functional aspects of cancer, at all stages of the disease trajectory from prevention through to bereavement” (Canadian Association of Psychosocial Oncology, n.d., para. 2).

Being interprofessional by nature, psychosocial oncology teams typically involve oncologists, social workers, psychologists, psychiatrists, oncological nurses, and other healthcare professionals, such as physiotherapists, and chaplains. Rodin commented that “psychosocial interventions that occur early in the course of a terminal illness have the potential for a greater duration of benefit, before progressive physical deterioration occurs” (2013, p. 926). As previously indicated, family members also experience heightened distress and struggle to cope with these issues. For this reason, psychosocial oncology is extended to caregivers, family members, and individuals providing support to a person living with cancer.

Palliative care is a non-curative care approach that relieves the suffering, improves the quality of life of individuals with life-threatening illness and integrates the needs of the family with the care of the patient (Gelfman, Meier, & Morrison, 2008; Hannon et al., 2015; World Health Organization, 2013). People dying from cancer represent individuals receiving palliative care. Canadian Virtual Hospice (2015, para. 2) outlined the following facets of palliative care:

- focuses on the concerns of patients and their families;
- pays close attention to physical symptoms such as pain, nausea, loss of appetite and confusion;
- considers the emotional and spiritual concerns of patients and families;
- ensures that care is respectful and supportive of patient dignity;
- respects the social and cultural needs of patients and families;
- uses a team approach that may include volunteers, social workers and spiritual leaders in addition to medical staff.

Palliative care is provided to individuals in hospital, hospices, or patients’ homes. Although commonly thought of as part of end of life care, palliative care is implemented at all
stages of an incurable or chronic illness (Hadad, 2008). Figure 1 illustrates palliative care and the trajectory of terminal illness (Ferris et al., 2002, p. 18).

**Figure 1. Palliative Care**

Advances in psychosocial oncology and palliative care have led to improvement in addressing and integrating the needs of patients living with terminal cancer and their caregivers who are typically spouses, parents or adult children (Bultz & Carlson, 2006; Gelfman, Meier, & Morrison, 2008; Howell et al., 2009). Yet advances in supporting the psychosocial needs of children coping with the anticipated death of a parent lag behind those of patients and caregivers. Due to developmental limitations, children’s psychosocial needs are challenging and complex, which can increase their vulnerability. Beale stated, “Children of palliative care patients present unique challenges for the palliative care professional. This group of children represents a hidden high-risk group whose needs are often minimized or overlooked by overwhelmed parents and are unknown to most of the medical staff” (2014, p. 1051).

**Summary of the Theoretical Framework Guiding This Doctoral Study**

It is important to briefly outline the theoretical framework which guided this doctoral study as it provided a lens through which this study was conducted. A detailed discussion of this framework will be outlined in Chapter Three. As there are many truths and realities with regard to children and families in general, and specifically living with, and dying from advanced cancer,
an epistemological position of social constructivism provided an understanding of how people interpret, perceive and construct knowledge (De Mol & Buysse, 2008; Gillies & Neinmeyer, 2006; Granvold, 2008). Co-construction of knowledge with a trusted adult facilitates a child’s understanding of serious life experiences such as cancer. Further refining the social constructivist position, Vygotsky’s Sociocultural Theory (1978) provided insight into children’s development, and more specifically, their understanding through social interactions, language, and culture construction (Bordova & Leong, 2007). Following this, the focus shifted to the relational theories of attachment and intersubjectivity to understand the bidirectional relationships and the emotional resonance shared by children and their parents. Finally, these relational theories were underpinned by the neurobiology of interpersonal relationships, and more specifically how humans use close relationships to gain and maintain “felt” security. This theoretical framework provided clarity and insight into the complexities of advanced cancer experienced by families.

Rationale for the Study

The rationale for studying this compelling issue focuses on the advancement of scholarly knowledge and social work practice and education. This section will outline both and will conclude with the purposes of the study and the research questions.

A Significant Issue for Scholarly Knowledge

There is a glaring dearth in the empirical literature addressing the experiences of children and parents coping with a parent living with, and dying from, advanced cancer. This dearth reinforces the murkiness of parental and professional understanding of children’s ability to cope. Absent from the research until the late 1990s, recent literature is limited with some attempts to fill the gaps. In addition, the empirical research does not go far enough. Ku¨hne et al. reiterated this stating, “Although the whole family is affected by a parent’s palliative disease, palliative
care research does not yet routinely consider patients’ minor children” (2012, p. 931).

Specifically absent from the literature is research focusing on children’s meaning making of terminal cancer, the threat to the emotional security of the attachment relationship with the ill parent, and the role of the surviving parent in understanding the nature of, and ameliorating the short- and long-term effects. As such, an undeniable need exists for more research such as this doctoral study to fully comprehend the myriad of issues faced by families, and the meaning children ascribe to the impending loss of their parent and emotional anchor. Beale summarized the importance of this compelling issue contending, “The short-term and long-term bereavement process of these children may be considerably mitigated by early intervention during the parent’s terminal phase, (2014, p. 1051).

A Significant Issue for Social Work Practice and Education

Social work represents one of the disciplines involved in psychosocial oncology and palliative care. Blacker and Deveau (2010) noted that social workers in palliative care provide intensive individual and family psychosocial support brought forth by a life-limiting diagnosis. With training in counseling, psychosocial needs, family systems, diversity, and community resources, Meier and Beresford (2008) contended that social workers play a significant role in supporting the patient and his/her family. In hospital oncology/palliative care departments, social workers provide short-term services for the psychosocial needs of the person dying from cancer, and the caregiver on an in-patient or out-patient basis. However, the experiences of the children coping with the complexities of their parents’ terminal illness and eventual death are rarely addressed in oncology clinics (Beale, 2014; Rauch & Muriel, 2004). Although parents often seek support from professionals, research revealed that resources for parents and children in oncology clinics are minimal at best. Those resources that are available focus primarily on aspects such as
disclosing initial diagnosis, and such resources are generally provided on request rather than a
standard of care (Phillips, & Lewis, 2015; Turner, 2004; Turner et al., 2007; Zaider et al., 2015).

Parents often seek support from community agencies to help the child through this time of
crisis. Social workers represent such a support, providing individual, family and/or group
interventions for children, parents, and families coping with this emotional time (Fearnley, 2012;
Huff et al., 2006; Kovacs, Hayden Bellin, & Fauri, 2006). Within the limitations of development
and life experience, children think and cope differently from adults, and interventions for
children must reflect this difference (Webb, 2007, 2011). Therefore, social workers should have
a solid theoretical and practice knowledge base in the provision of developmentally appropriate
interventions, helping children to make sense of the “muddle arising from adverse experiences in
their lives” (Winnicott, C. 1964 as cited in Kanter, 2004).

As Webb (2007) contended, however, findings of practice based empirical research
indicate a lack of educational preparation for social worker about issues of dying and death.
Social workers experience “a strong sense of helplessness” (Huff et al., 2006, p. 222), and are
often “not as prepared as they need to be or would like to be to be” (Csikai & Raymer, 2005, p.
53). This helplessness and unpreparedness can magnify tenfold when supporting a child. Clarke
and Mevik noted a “continuing disjunction between new understandings of children and
childhood and social work education and practice” (2008, p. 30). Clarke and Mevik further stated
that “teaching and learning continues to focus on highly abstracted, idealized conceptualization
of childhood with little opportunity to provide students with opportunities to obtain a grounded
understanding of children’s interaction with their world” (p. 35). Such conceptualization does not
support real world crises experienced by children, or realistic intervention strategies facilitating
positive outcomes.
Therefore, “if professionals are to be able to offer good care, their knowledge of the children’s perspectives must be extended” (Buchwald, Delmar & Schantz-Laursen, 2012, p. 229). As such, developing a comprehensive theoretical and practical foundation of supporting a child living with a terminally ill parent has extensive implications for social work education and practice. Children have much to “say” (verbally, non-verbally, and through play) and it is up to trusted adults such as social workers to “listen”.

Accessing children’s mental health services in Ontario. Further to these issues is the stark reality that for many families supports such as therapy for children and families are often out of reach financially. Moreover supports may not inclusively address and accommodate all aspects of diversity (such as culture, family type, gender, and ability). A further confounding variable is the average wait time for children’s mental health services. The Pre-Budget Submission 2016 for Children’s Mental Health Ontario indicated, “Currently in Ontario, more than 6,500 children and youth with significant mental health issues are waiting for more than a year to access treatment while demand for services continues to grow by 10% per year” (p. 3).

Such barriers to accessing therapeutic support may compound a child’s ability to endure the anticipated and actual loss of their parent and emotional anchor, adversely affecting short- and long-term outcomes.

Purposes of Study

Incorporating the voices of children and parents or caregivers to develop a rich understanding of the lived experiences of children and their parents or caregivers when a parent is living with, and dying from, advanced cancer was the primary purpose of this doctoral study. This understanding was achieved through: (1) the parents’ perspectives; (2) the parents’ perspectives of their children’s experiences; and (3) the children’s perspectives.
Providing current and relevant research informing the identified gaps in the literature, and social work education and practice represented the secondary purpose. This facet of research can address the lack of preparedness identified in the literature through curriculum and professional development designed to support social workers in their work with children and families experiencing the distress and uncertainty of advanced cancer.

The final purpose focused on this research providing the foundation for supporting the creation of developmentally appropriate child/family centred short- and long-term support strategies. Such strategies will assist children’s immediate support systems and communities in better meeting the needs of children during this time of heightened distress, thereby leading to positive outcomes.

**Research Questions**

The vulnerabilities of children and parents during such an overwhelming time, in addition to the purposes indicated, represent significant rationale for this doctoral research. The research questions which guided this interpretive inquiry are:

1) How do children and their parents (ill parents and well parents or caregivers) construct meaning of the parent’s cancer?

2) How do children and their ill parents, well parents or caregivers talk about coping with the parent’s cancer (specifically the threat to children’s emotional security and perceived changes to the attachment relationships, the child’s sense of self and social location)?  
3) What is the experience of children and their ill parents, well parents or caregivers with formal and informal supports within and outside the cancer centre?  
   a) What do children and parents find helpful and unhelpful in coping with the parent’s cancer?  
4) How can the experiences of both children and parents or caregivers better inform social work education and practice, in turn supporting the creation of developmentally appropriate short- and long-term support strategies for children and families coping with a parent’s advanced terminal cancer?
**Methodology**

“Through sharing the worlds of our subjects, we come to conjure an image of their constructions and of our own” (Charmaz, 2000, p. 529). Qualitative methodology is appropriate for this doctoral study to assist in exploring another’s world or reality, in turn capturing the essence of their experiences through rich narratives (Creswell, 2002; Durrheim, 2006; Kvale, 1996). The following section outlines a summary of the methodological approach for this doctoral research. This approach will be expanded upon in Chapter Four of this dissertation.

**Methodological Approach**

There are many qualitative approaches to assist in exploring another’s world or reality. Phenomenology represents one approach which van Manen contended is “more a method of questioning than answering, realizing insight comes to us in that mode of musing, reflective questioning and being obsessed with sources and meanings of lived experience” (2014, p. 27).

**Hermeneutic Interpretative Phenomenology**

In reflecting on a phenomenological approach that would best capture the experiences of children and their parents or caregivers, hermeneutic interpretive phenomenology informed by Heidegger and Gadamer was chosen. Cole stated, “it is this move to interpretive practice that marks a key distinction between purely phenomenological research seeking rich lifeworld descriptions of the lifeworld, and hermeneutic phenomenological research that seeks to understand these worlds from participants’ perspectives” (2010, p. 1). Based on Heidegger’s assertion that meaning is co-developed through shared humanness and life experiences, this approach facilitates the exploration of meaning to gain an understanding of how people make sense of their experiences (Cohen, Kahn, & Steeves, 2000; Crist & Turner, 2003; Moustakas, 1994; Smith, 2003). Heidegger considered research as a circular process inclusive of culture and
history, incorporating the Hermeneutic Circle through which the understanding of texts is distilled to a place of sensible meaning (Laverty, 2003; Smith, 2003). The work of Gadamer will also inform this doctoral research. As a constructivist, Gadamer argued that human understanding is inter-subjective (Jones, 2004). Fleming, Gaidys and Robb (2003, p. 117) noted, “Gadamer believed that understanding and interpretation are bound together and interpretation is always an evolving process, thus a definitive interpretation is likely never possible.” As such, hermeneutic interpretive phenomenology informed by Heidegger and Gadamer is congruent with this research which uncovered and developed an understanding of the complexities and meaning of the experiences of children and parents coping with incurable illness such as advanced cancer.

**Study Location, Sample Size and Interviews**

This study was conducted at the Princess Margaret Cancer Centre, University Health Network, Toronto, Ontario. Patients with terminal cancer with an expected survival of less than 24 months, well parents or caregivers and children formed the basis of the sample. The sample size consisted of seven families. This sample size was appropriate for a phenomenological study with the goal of obtaining a varied and deep understanding of the participants’ experiences (Creswell, 2002; Kreuger & Neuman, 2005; Smith, & Osborn, 2003). Digitally audio recorded, face-to-face, semi-structured interviews with children, well parents or caregivers, and ill parents formed the basis of the data collection. Such interviews enabled children and parents or caregivers to provide a personal narrative of their experiences, fitting with interpretive research (Moustakas, 1994; Sarantakos, 2005).

**Ethical Issues - Vulnerable Populations and Sensitive Research Topic**

As this doctoral research involved vulnerable populations and a sensitive research topic, ethical considerations were of importance, particularly ensuring the wellbeing of research
participants. Dobratz (2003) commented that “knowledge acquisition is subordinate to participant wellbeing (as cited in Campbell-Crofts et al., 2013, p. 74). Research involving children coping with a parent’s terminal illness and anticipated loss must be undertaken with utmost sensitivity. The Research Ethics Guidebook indicated:

The ethics of research with children is a balance. On the one hand, the focus is on ways of preventing and reducing harms in research and ensuring adequate protection of children and young people. On the other hand, there is concern about the risks and harms of silencing and excluding children from research about their views, experiences and participation. (Research with children, n.d., para 2)

This study received Institutional Approval from the Research Ethics Board of the University Health Network (Princess Margaret Cancer Hospital), in addition to the Research Ethics Board of the University of Toronto. To obtain approval, this doctoral candidate provided specific details of all ethical considerations. Consent of adults and assent of children were key ethical considerations. In order to include the voices of children in the research, parents’ consent permitting their children to participate was needed. Following this, gaining the assent of the children was needed for them to participate. This process, in addition to the challenges experienced in obtaining parental consent, is fully outlined in Chapter Four of this dissertation.

Analysis

Data analysis was interpretive and on-going in nature and looked for clusters of meaning, assumptions, patterns, and themes to develop a rich textual “restorying” true to the essence of the experiences of the participants (Riessman, 2008). Reflective of the rich data collected in this phenomenological study, an inductive approach was utilized. This involved a process of layered reading, extracting statements, formulating meaning, clustering and validating themes, and
synthesizing meanings and essences (Smith, Flowers & Larkin, 2009). Such an analysis enabled themes to emerge from the participants’ stories to form a comprehensive picture of the phenomenon (Mills, Bonner, & Francis, 2006). Both individual themes of participants and collective themes that occur across the group of participants were part of the analysis. The intent of this analysis was to gain a detailed understanding true to the essence of the complexities of parents’ advanced care as experienced by children and their parents/caregivers.

**Organization of This Dissertation**

From this introductory chapter it can be seen that there is much to learn about the myriad of issues faced by families coping with advanced cancer. This is particularly evident with the meaning children ascribe to the impending loss of their parent and emotional anchor, and how best to support children and parents. With the aim of furthering the learning and understanding, this dissertation is divided into six chapters. This introductory chapter is followed by Chapter Two which will provide a synthesis and critical analysis of the extant empirical literature related to the anticipated loss of a parent due to advanced cancer. This chapter will give context to the issue and provide evidence for the meagreness of the relevant literature.

Following a review of the literature, Chapter Three will situate the issue in a theoretical framework chosen to provide insight into the needs of children and parents living with the uncertainty of advanced cancer and loss. This chapter will conclude with a theoretical model illustrating the various facets of the framework guiding this study.

Chapter Four will describe the research design, hermeneutic interpretive phenomenology, in general. An extended rationale for incorporating this methodological approach together with a detailed description of the research process will be outlined. The final focus of this chapter will include strategies to ensure rigor and trustworthiness in this qualitative study.
Presentation of the research findings will encompass Chapter Five. The discussion will concentrate on the emerging themes as they arose from the data. Exemplars from participants will be included to illuminate the lived experiences and themes. This chapter will provide an analysis and interpretation of the findings according to phenomenological methodology. Interpretation is seen as critical to this process of understanding (Laverty, 2003). Through this detailed interpretation and analysis, this chapter will illuminate the essence of the phenomenon of the lived experiences of children and parents coping with a certain death at an uncertain time.

Chapter Six, the final chapter, will present a summary of the findings. Limitations and potential contributions of the study will be outlined. Implications with respect to scholarly knowledge, social work practice and education, and social policy will also be discussed. Recommendations for future research will comprise the final section of this chapter.

In conclusion, this doctoral research presented a much needed advancement of the understanding of experiences of children and parents coping with the uncertainties of advanced cancer and anticipated death. Supporting children and families during the dying time represents a critical social issue and issue for social work practice and education. Christ (2000) made a case for such research stating that a clear understanding of children’s psychosocial needs “may be missed if the period before the death is not included in future studies” (p. 19).
Chapter Two
Synthesis and Analysis of the Empirical Literature

Children are deeply affected by cancer in a parent. There is potential for children’s developmental outcomes and well-being to be compromised due to the potential consequences of living with a parent’s terminal illness and anticipated death (Beale et al., 2004; Bugge et al., 2008; Christ, 2000; Christ & Christ, 2006; Kennedy & Lloyd-Williams, 2009a, 2009b). As such, there is a critical need for research to provide insight into the lived experiences of children and their parents or caregivers coping with a parent’s advanced cancer and anticipated death. The purpose of this literature review was to identify the gaps in the extant research that, if addressed, could advance the theoretical and practice knowledge base. Such gaps support the research questions in this doctoral study (outlined in Chapter One). Worry or distress, the threat to children’s emotional security and perceived changes to the attachment relationships represent the specific interest of this doctoral research.

An additional purpose of the literature review was to identify factors related to the experiences of children and parents coping with advanced cancer which promote or compromise well-being. To facilitate an understanding of these issues, the literature reviewed was presented thematically. Several themes were discussed as they related to children directly and/or to parents or caregivers.

Following the thematic presentation, an analysis of the meager literature directly relevant to the focus of this research has been included to provide an account of how the current literature represents the voices of children and parents. The ways in which the respective authors contributed to the understanding of this phenomenon were examined. Strengths and needs of the literature were identified. In addition, identifying what was missing from the discussion supported the need for specific research such as that represented by this doctoral study.
Process of Conducting the Literature Review

The initial focus of the literature review was related to the experiences of children and parents coping with a parent living with, and dying from, advanced cancer. Through various searches, the dearth of relevant literature became apparent. The limited empirical literature provided some understanding of perspectives of the parent living with advanced cancer and of the well parent or caregiver. Additionally, the parents’ perceptions of their children were included to some extent. Yet, the voices of children and adolescents were represented in only five studies conducted between 2000 and 2009. Four recent studies (2011 to 2015) focused solely on adolescents. From the little attention given directly to children, an understanding of their experience has remained murky at best.

In light of the dearth of the literature, the focus of the review was widened to research related to families coping with early stage, or non-life threatening cancers. A body of literature does exist with the emphasis on parents’ concerns related to adaptation to illness, treatment and its effects, emotional distress, and how to communicate with children. This literature represents a strength as it provides a reference point for general understanding of families living with a parent diagnosed with cancer. However, it also represents a weakness as it does not further the specific understanding of the issues directly related to advanced cancer and families. Literature in relation to parenting and caregiving, and palliative care and anticipatory loss was also reviewed, adding insight to this study’s focus. Finally, research associated with cancer health disparities and advanced cancer was reviewed, and as indicated in Chapter One, although not part of the research questions, these issues did provide some understanding in relation to advanced cancer. Therefore, the review of these aspects of the literature formed the basis of the synthesis and analysis of this chapter.
Thematic Presentation of the Literature

The following section provides discussion of the common themes present in the literature. Each theme has been discussed in relation to children and/or parents to facilitate an understanding of the issues and needs of families coping with the complexities of advanced cancer, and anticipatory loss.

Anticipatory Loss

Hope against hope can describe individuals coping with the gravity of the impending loss of a loved one from terminal illness such as advanced cancer. Such loss is termed anticipatory grief in the empirical literature. Anticipatory grief is described as a “range of intensified emotional responses that may include separation anxiety, existential aloneness, denial, sadness, disappointment, anger, resentment, guilt, exhaustion, and desperation” (Cincotta, 2004, p. 325). Although similar to traditional grief following the death of a loved one, anticipatory grief differs with regards to timing. Anticipatory grief is often experienced by patients with incurable illness and their families from the point of diagnosis (Bell & Ristovski-Slijepcevic, 2011; Hottensen, 2010; Saldinger & Cain, 2005; Wong & Chan, 2007). Rolland (1990) noted, “A family's experience of threatened loss varies with the kind of illness, its psychosocial demands over time, and the degree of uncertainty about prognosis” (p. 1).

In his seminal research with wives of soldiers fighting in Europe during the Second World War, Lindemann (1944) found that each wife experienced what could be typical grief. He noted that their reaction could be thought of as a way of protection because actual loss was a very real outcome. Lindemann described this reaction as anticipatory grief. Further to Lindemann’s work, it has been proposed that anticipatory grief for the dying person, family and friends parallel that of post-death grief (Raphael, 1983). Rando (1986) advanced Lindemann’s work as she
conceptualized anticipatory grief to be a multidimensional concept, and more specifically, “the phenomenon encompassing the processes of mourning, coping, interaction, planning, and psychosocial reorganization that are stimulated and begun in part in response to the awareness of the impending loss of a loved one (death) and in the recognition of associated losses in the past, present, and future” (p. 24).

Disagreement exists in the literature about the positive or negative aspects of anticipatory grief. Ponder and Pomeroy indicated that, “Persistent debate remains about whether anticipatory grief results in shorter and easier periods of grief when the actual death occurs or … may have adverse effects” (1996, p. 4). Positive aspects relate to knowing a death of a loved one is approaching and the opportunities this presents for both the person dying and their loved ones. Sweeting and Gilhooly (1990) suggested that emotions can be rehearsed during anticipatory grief. In addition, anticipatory grief may enable the person dying and loved ones to acknowledge the “mini-losses” as the person moves closer to death. Through a review of the literature, Reynolds and Botha (2006) related that anticipatory grief facilitates the leave-taking process providing time to complete the unfinished business of life. The concept of a “good death” has been associated with this process of grieving ahead.

Negative aspects focus primarily on cumulative and draining effects of terminal illness. Sullivan (2003) commented on the negative aspect of the hopelessness of the situation as experienced by the dying person as well as the survivors. Additionally, through a qualitative investigation of thirty spouses caring for a partner dying of cancer, Saldinger and Cain (2005) illuminated the cumulative and draining effects in the following:

Traumatic helplessness featured prominently in the emotional responses of well spouses.

Without exception, they were exposed to multiple circumstances that shattered their
assumptive world, heightened their emotional reactivity, assaulted their visual and auditory senses, and rendered them anxious about the final break with their dying spouse. (p. 88)

As such, Saldinger and Cain made a case to de-romanticize anticipated death as the ‘good death’ concluding that “terminal illness presents couples with stressors that outweigh, and often preclude, the benefits of forewarning” (p. 89).

Moreover, medical research has advanced treatments for various types of cancer, which often extend life. Dying for many people with cancer is now a gradual process of steady decline. This extended time has implications for anticipatory grief. Hottensen (2010) commented that patients with advanced cancer and their families often experience anticipatory grief from the point of diagnosis. Bell and Ristovski-Slijepcevic (2011) conducted ethnographic fieldwork with six women living with metastatic breast cancer in Canada, to gain a detailed understanding of the mothers’ experiences while facing a contracted future. Findings indicated that mothers living with metastatic cancer are faced with “coming to grips with the knowledge that it is not a matter of if their cancer will kill them, but when” (p. 631).

**Children and Anticipatory Loss**

Children living with a parent with incurable cancer regularly think about, and fear, the death of their parent (Bugge et al., 2008). Buchwald et al. (2012) conducted a qualitative study in Denmark, from a nursing orientation, with seven children from 11 to 17 years of age to investigate how children cope when a parent is dying. From this research, the authors proposed the term “death’s waiting room [which] illustrates that, in the place where they live their lives with their friends and families, with joys and anxieties, they now await death, which is lurking round the corner” (p. 231).
Eight bereaved families with children aged six to sixteen formed the sample for research conducted by Saldinger et al. (1999) in Michigan with the purpose of investigating the presumed benefits of anticipatory loss such as having a head start on grief work; saying good-bye or emotional closure; and planning for the future. The results indicated that terminal illness creates cumulative stressors that are compounded by children’s developmental limitations in understanding the impending death. Parents may experience a reduced capacity to attend to a child’s emotional needs, heightening the confusion and distress. The authors concluded that parents’ anticipated death is consistently associated with less adaptive outcomes and that “palliative illness is more stressful than bereavement” (p. 41).

In a review of the literature focusing on adolescents coping with the impending loss of a parent from advanced cancer, Phillips (2014) cited a lack of benefit from anticipatory loss. This author indicted that coping with a parent’s advanced cancer may be a particularly vulnerable period for adolescents with respect to “the loss of a healthy parent, the loss of both parents’ emotional and physical availability, and the loss of normalcy in their family lives” (p. 1324).

Siegel, Karus, and Raveis (1996) conducted a quantitative study which compared the levels of depression and anxiety among children aged seven to seventeen before and after the loss of a parent to cancer. The authors’ research revealed “children’s levels of depression and anxiety prior to their parent’s death were significantly higher than it was seven to twelve months after the loss of their parent. This suggests that the terminal phase of a parent’s illness may in fact be a period of more distress than after the actual loss” (p. 448).

Therefore, the literature clearly indicates that the terminal phase of a parent’s illness, such as advanced cancer, may be a period of greater psychological stress for children than the actual loss and bereavement. Moreover this phase may pose detrimental implications for children’s
long term outcomes (Christ, 2000; Dunning, 2006; Kennedy & Lloyd-Williams, 2009a; Phillips, 2014; Saldinger et al., 1999; Saldinger et al., 2004).

**Emotional Distress**

Distress experienced by individuals living with cancer, their caregivers, and family members has become the subject of empirical research (Dumont et al., 2006; Given, Given, & Kozachick, 2001; Rodin et al., 2009; Thastum et al., 2008). As a result, emotional distress has been recognized as an indicator of psychosocial well-being, and has been deemed the sixth vital sign (Bultz & Carlson, 2006). The Pan-Canadian Clinical Practice Guideline (Howell et al., 2009) recommends that professionals providing psychosocial support should screen individuals (patients and caregivers) for distress to assist in identifying those who are struggling. Such screening should encompass the physical, informational, psychological, social, spiritual, and practical domains. The research led to the development of assessment measures such as the Edmonton Symptom Assessment System (Bruera et al., 1991). This measure was designed for patients and has been adapted for caregivers.

The emotional distress experienced by parents (patient and well parent) living with, and dying from, advanced cancer is illuminated in the research. Situated in Denmark, Thastum et al. (2008) conducted a qualitative study with fifteen families to investigate coping, social relations, and communication in families. The authors indicated that the level of a parent’s distress is exacerbated if he/she has dependent children. In a study of eight women newly diagnosed with metastatic breast cancer, Turner, Kelly, and Swanson (2005) reported that distress of mothers is exacerbated “by grief and guilt about the impact on their children and uncertainty about how to talk with their children about the diagnosis” (p. 396). Additionally, Bell and Ristovski-Slijepcevic (2011) discussed the term “hierarchy of suffering” in their study on mothering and
metastatic cancer as “an oftentimes unspoken agreement that living with advanced cancer was far worse when the women had dependent children” (p. 634).

Similar to the parent with cancer, emotional distress becomes the lived experience of well parents. Through a review of the literature focusing on the effects of advanced cancer on the well parent, Aamotsmo and Bugge (2014) concluded that healthy parents set aside their own needs and feelings to be available to the needs of their partners and children. The authors illuminated this stating “their role as a flexible ‘jelly man’ can be experienced as a stressful balancing act similar to tightrope walking, where one could easily slip and fall to either side” (p. 324).

**Children’s Emotional Distress**

Due to developmental limitations and limited life experience, children are the most vulnerable members of families coping with terminal cancer. The deterioration of a parent, the lack of certainty in the present and future, in addition to the threat of death of their parent may cause long-term negative psychosocial outcomes for children and adolescents. Children’s distress is complex, resulting in potentially higher rates of depression, anxiety, and lower self-esteem (Beale et al., 2004; Bugge et al., 2008; Christ, 2000; Christ & Christ, 2006; Kennedy & Lloyd-Williams, 2009a; Phillips & Lewis, 2015).

In general, as children grow, they are more able to cope with stressful events, having felt needs met. At times, children rely on the assistance of trusted adults to bolster their ability to cope. When the stressful event seems insurmountable as with the anticipated death of a parent, and the ongoing situation affects the emotional availability of trusted adults, children’s felt needs for security may not be met. Overwhelming feelings of fear and vulnerability can create great emotional distress. Siegel et al. noted, “Children facing the impending death of a parent due to
cancer reported higher mean levels of psychological distress than a sample of similarly situated community children weighted to reflect the same age and gender distribution” (1996, p.448).

Research has revealed that adolescents coping with parental cancer demonstrate greater anxiety, depression, distress, diminished social competence and school performance than school-age children (Phillips, 2014; Phillips & Lewis, 2015; Rainville, et al., 2012; Visser et al., 2004). Developmental gains give adolescents a greater understanding of the impact of terminal cancer and realization of the parent’s inevitable death. Christ et al. (1993) contended, “Compared to younger children, the adolescents’ greater cognitive and empathic capacities allowed them to be more aware of losses and of the parent’s physical and emotional pain” (p. 604).

The research therefore provides consistent evidence of the significant emotional distress felt by the children. Parents’ own emotional distress and mitigating factors like caregiver burden can compound children’s emotional distress.

**Caregiver Burden**

Formal health care and the community in general have recognized the importance of the role of the family caregiver in supporting a person living with a terminal illness such as advanced cancer. As health care systems are being re-structured due to resource limitations, family members are increasingly more responsible for caregiving. In Canada, 80–90% of the care individuals receive in their homes is provided by family caregivers (Romonow, 2002 as cited in Stajduhar et al., 2010). In an American study of 25 caregivers for individuals with brain tumours, Schubart, Kinzie, and Farace (2007) stated, “Family caregivers provided extraordinary uncompensated care involving significant amounts of time and energy for months or years and requiring the performance of tasks that were often physically, emotionally, socially, or financially demanding” (p. 1).
Research has focused on the detrimental effects of caregiving, specifically caregiver burden, in light of the multiple roles held by a caregiver. Added to the extensive caregiving is the spouse’s own distress at the reality of losing his/her life partner. Caregiver burden is the cumulative distress specific to caregiving, and differing from anxiety, depression, and other emotional responses (Given et al., 2001). Research has reported some concerning findings; specifically a lack of self-care, increased anxiety, depression and physical health concerns. Spouses caring for their partner living with, and dying from, cancer have as much or even higher distress than patients particularly as the patient’s status deteriorated (Aamotsmo & Bugge, 2014; Dumont et al., 2006; Golant 2008; Goldstein, 2004; O’Hara et al., 2010). In a Canadian longitudinal study focusing on caregiver burden associated with 89 caregivers for women dying from breast cancer, Grunfeld et al. (2004) concluded, “caregivers' depression and perceived burden increase as patients' functional status declines” (p. 1795). They also noted, “Caregiver burden was the most important predictor of both caregiver anxiety and depression” (p. 1800). These findings were echoed in another Canadian study conducted by Dumont et al. (2006) on the psychological distress of 212 caregivers caring for a family member with advanced cancer. The authors indicated that caregiver distress/burden is strongly associated with the progression of the patient’s disease, and noted, “Caregivers should not be considered only as partners in caring but also as potential patients” (p. 918).

In families with young children, the caregiver is often the well parent. In such circumstances, caregivers takes on a double role; caring for dependent children and the spouse who has terminal cancer, in conjunction with the household tasks, often while working to compensate for the depleted household income. This has the potential to overwhelm a parent who is also coping with his/her own worry about losing a partner. Doing more with less may
typify the experience of a caregiver who is a partner and parent. Aamotsmo and Bugge (2014) referred to the well parent’s double role as “balancing artistry” and “new roles without a script” specifically indicating, “The healthy parent in these papers expressed being torn between the needs of their ill partner and those of their children. Despite facing practical and emotional challenges of balancing the different needs of family members with vitality and determination, they expressed feeling inadequate” (p. 323).

Caregiver distress and burden are cumulative risks that have significant consequences to parenting efficacy, affecting the emotional well-being of the children. A parent’s ability to be physically and emotionally available to their child is dramatically affected, which can impact a child’s ability to cope with impending loss. In a review of the literature focusing on reasons why the needs of children are not addressed in routine cancer care, Rauch and Muriel (2004) contended that while acting as a caregiver and parent, the well parent’s sense of competence to meet their children’s needs declines, especially with regard to emotional sensitivity, responsiveness, and discipline. This was reiterated by Kühne et al. (2012) who stated, “due to psychosocial stress, healthy spouses may have difficulty adequately meeting their children’s needs, which may in turn exacerbate their children’s situation” (p. 931). Studies have also emphasized the importance of the surviving parent in supporting the adjustment of the child after the death (Dunning, 2006; Saldinger et al., 2004; Worden, 1996). If the parent is depleted emotionally and physically from pre-death caregiving, it may have a negative spin off for children’s future outcomes.

Parenting: the Dying Parent’s Experience

Advanced cancer dramatically affects parenting for both the well parent and the ill parent. Research also illustrates the effects experienced by dying parents. Semple and McCance (2010)
conducted a literature review of the experiences of parents living with cancer who have children. They indicated three major concerns of parents facing terminal illness: parental competence (being a good parent); communication with children (how to talk about illness); and maintaining routines at home (the need to maintain normalcy). The authors related that the ill parent felt pressure to maintain normality, however doing so became increasingly more difficult with increased fatigue, pain, and disability. The important need to maintain normalcy for children in abnormal situations was a theme in several studies (Elmberger, Bolund, & Lützén, 2000; Houldin, & Lewis, 2006; Kennedy & Lloyd-Williams, 2009a; Phillips, 2014).

Turner et al. (2007) confirmed this need for normalcy as being particularly evident for mothers despite living with the deleterious effects of their disease. Keeping a routine and structure in their children’s lives would make children feel safe and grounded. Furthering the research, Bell and Ristovski-Slijepcevic (2011) focused specifically on mothers with metastatic cancer facing a contracted future. The authors concluded:

Mothers expressed a sense of inauthenticity in relation to their interactions with their children. Metastatic cancer had forced them to try and cram a lifetime’s worth of parenting into a few short years. They had only a short period of time to mould both the present and future selves of their children—cram parenting. (p. 642)

With regard to fathers with advanced cancer, research by Elmberger, Bolund, and Lützén. (2002) situated in Germany focused on eight fathers with blood based cancers. The authors concluded that in addition to the need for normalcy and safety for their children, fathers experience changes in self-image as men and as parents, and struggle to find their new role. “The role of a hard-working man had been replaced by the role of a weak father at home” (p. 480).
Parenting as a priority was cited by Phillips (2014) in her study focusing on parents with advanced cancer whose children were adolescents. Phillips labeled this theme “Making the Most of the Time We Have Left Together”. She noted “the sicker parents became, the more parenting and their relationship with their children became a chief concern in their lives” (p. 1331).

The research provides insight into the importance of parenting and relationships for parents living with, and dying from, advanced cancer. This could be understood as “sustaining ‘double awareness’ of the possibilities of life while also facing the end … the challenge for those who are both living and dying” (Rodin, 2013, p. 926).

**Living with Uncertainty**

Uncertainty experienced by patients and family members defines many illnesses, and can become immobilizing when facing the impending death of a loved one (Buchwald et al., 2012; Christ, 2000; Kennedy & Lloyd-Williams, 2009a; Sheehan & Draucker, 2011). Uncertainty can be seen as "the inability to determine the meaning of illness-related events, assign definite values to objects and events, and/or accurately predict outcomes" (Mishel, 1988). Uncertainty in Illness Theory was developed by Mishel in relation to the uncertainty experienced by parents whose children are living with potentially fatal chronic or acute illness (such as paediatric cancer). She conceptualized that uncertainty in of itself was “neutral”. If this uncertainty is perceived as a danger, as with terminal illness, it can result in significant psychological distress.

In the face of advanced or terminal cancer, one could posit that Uncertainty in Illness Theory can also conceptualize the level of uncertainty experienced by children and their parents. From their parent’s diagnosis, through treatment, to palliative care and death, children must cope with much uncertainty. Buchwald et al. (2012) concluded:

Living with a dying mother or father exposes children to high levels of stress and they experience changes in their social relationships with potentially damaging psychological
consequences. These children think about death, and their sense of security is affected when they are confronted with the prospect of a parent’s death. (p. 228)

It can be hypothesized that in light of the cumulative stress experienced over the duration of their parent’s illness, the uncertainty of this emotionally charged experience can be perceived as a danger by children. Arkitel (2015) indicated that teenagers describe “an everyday life where uncertainty is ever present like a shadow” (p. 8). This perception would be the same for parents coping with their own uncertainty regarding the illness and its impact on future hopes, and security (Saldinger & Cain, 2005). The uncertainty experienced by the adults and children could reciprocally affect and resonate with each other’s emotional distress.

Parents’ Perceptions

Illness can be an “uninvited guest that must be incorporated into family life” (Rolland, 1999, p. 251). The literature indicated a tendency on the part of parents and family members to underestimate the degree of impact the parent’s deteriorating status from advanced cancer and the impending death has on the child. The results of Turner’s systematic review revealed that “although the emotional burden for families and children of young mothers with advanced breast cancer is considerable, it appears that parents may fail to recognize or respond to this distress” (2004, p. 61). Turner’s findings were validated by Huizinga et al. (2003) through their research which explored “the psychosocial functioning of Dutch children who have a parent treated for cancer and the variables that may positively or negatively relate to the development of emotional and behavioral problems” (p. 196). The researchers conducted a retrospective cross-sectional study with fourteen patients, twelve well parents, and fifteen children, and concluded:

Parents’ reports of the emotional and behavioral adjustment of their children in the months
after diagnosis seem to differ from those of the children. Whereas the children report a negative impact on their self-esteem and adaptation, their parents report that the children experience minimal behavior or emotional problems. (p. 195)

With regard to the father/child relationship, Forrest, Plumb, Zieland, and Stein (2009) conducted research in Britain focusing on fathers’ roles and communication with their children when mothers have been diagnosed with breast cancer. The results of the study revealed a disparity between the perceptions of fathers and their children. Fathers underestimated children’s distress, presuming their children were reassured, but children’s reports did not indicate this. Kennedy and Lloyd-Williams (2009a) contended that parents felt their children were coping with the situation, whereas children’s self-reports indicated they struggled emotionally. Thus, the research indicates that parents underestimate the impact of a parent’s palliative status on the children. The reasons for the misperception vary. Beale (2014) stated, “There is a common belief among parents and caretakers that children are generally adaptive and that they will adjust to their circumstances (p. 1051). Beale added “parents and caretakers sometimes voice the belief that children, particularly younger ones, do not really understand what is going on and, therefore, it is best not to discuss the situation with them” (p. 1051).

The strong need on the part of parents and families to protect children from overwhelming pain represented an additional theme in the literature. Some parents choose to keep the truth of the situation from the child or to limit the discussion (Beale et al., 2004; Turner, 2004). Children have innate ‘radar’ to the emotional tenor of the household however, and despite being protected from the truth, they are very aware that something significant is happening. The children’s lack of direct knowledge results in confusion, heightening their anxiety and insecurity.
Communication

Communication is an important factor facilitating children’s adjustment to their parent’s illness, and psychosocial well-being. Talking about serious illness and anticipated death can be difficult to think about, however, research has indicated that such conversations support children in their ability to cope with such a crisis (Fearnley, 2012). However, parents struggled with whether they should tell their children, in addition to the amount of information, timing, and language used to explain cancer (Fearnley, 2012; Kennedy & Lloyd-Williams, 2009b; Phillips, 2014; Turner et al., 2007).

Various aspects of communication in families coping with terminal cancer was one of the areas consistent in the literature. Forrest et al. (2009) indicated that reactions of younger children were similar to older children; shock, emotional upset, fear, and anxiety and the reactions were exacerbated if the father/child communication was impeded. The researchers found that children as young as seven years of age were more aware of the life threatening nature of cancer than parents realized. These findings were similar to those of Thastum et al. (2008) who indicated:

Children observed that the healthy parent was sad and suffered from great stress, but apparently they seldom talked to the children about their feelings. The children deduced the healthy parent’s mental state from his behaviour or facial expression, not from what they were told. (p. 131)

Through their qualitative research involving twelve families focusing on communication and children’s need for information, Kennedy and Lloyd-Williams (2009b) reiterated the importance of communication and providing information in a study exploring children's need for information when a parent was dying of advanced cancer. Communication was described as a critical aspect to positive outcomes for children. Children were able to articulate their wishes.
They wanted personal information about their parent’s cancer from parents, and factual information from health professionals, books, and internet. Communication was “associated with barriers such as children not wanting to distress their parents and vice-versa” (p. 153). Further to this, Bugge et al. (2008) noted, “Children had questions to ask but had not dared to ask them. They thought that their questions would upset their parents and were thus reluctant to voice their questions or concerns” (p. 430).

Adolescents’ needs regarding communication are documented in the research. Sheehan et al. (2014) researched how parents tell adolescents bad news, their parent was going to die. The authors looked at what made bad news easier to swallow. They found that parents did this in one of four ways: measured telling, skirted telling, matter-of-fact telling, and inconsistent telling (p. 515). A summary of the ways of telling provides insight as presented in the following table:

<table>
<thead>
<tr>
<th>Table 2. Ways of Telling (Sheehan et al., 2014)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Measured telling</strong> (p. 515)</td>
</tr>
<tr>
<td>Description of Style</td>
</tr>
<tr>
<td>Parent(s) told adolescent(s) about the serious illness or imminent death of the ill parent in a way that was thoughtfully considered.</td>
</tr>
<tr>
<td>Measured telling seemed to be the “model” for a healthy way of telling.</td>
</tr>
<tr>
<td>Parent-Adolescent Interaction</td>
</tr>
<tr>
<td>The interactions between parents and adolescents in measured telling are transactional. The parents continually assessed the adolescents’ responses to information they were given and adapted their telling accordingly.</td>
</tr>
<tr>
<td>The adolescents communicated either directly or indirectly to their parents about how much information they wanted and how they wanted to receive it.</td>
</tr>
<tr>
<td>Outcomes</td>
</tr>
<tr>
<td>The outcomes of measured telling were always positive. The adolescents felt well-informed but not overwhelmed.</td>
</tr>
<tr>
<td><strong>Skirted telling: Beating around the bush</strong> (p. 515, and p. 517-518)</td>
</tr>
<tr>
<td>Description of Style</td>
</tr>
<tr>
<td>Parent(s) told the adolescent(s) about the illness/imminent death of the parent in a way that was indirect or ambiguous. The parents did not hide the truth or lie to the adolescents, but avoided revealing information “straight out.”</td>
</tr>
<tr>
<td>Parents bypassed the more difficult information in order to make the disclosure easier for the adolescents.</td>
</tr>
<tr>
<td>Parent-Adolescent Interaction</td>
</tr>
<tr>
<td>-------------------------------</td>
</tr>
<tr>
<td>Outcomes</td>
</tr>
</tbody>
</table>

**Matter-of-fact telling: Having a conversation** (p. 518)

<table>
<thead>
<tr>
<th>Description of Style</th>
<th>Parent(s) told adolescent(s) about the serious illness or imminent death of the ill parent in a way that was factual and unemotional. These disclosures revealed news about the ill parent but focused on practical issues rather than emotional.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Parent-Adolescent Interaction</th>
<th>The interactions between parents and adolescents in matter-of-fact telling were instructive. The parents provided information that the adolescents “needed to know,” and the adolescents received the information dispassionately, embedded in daily conversations.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outcomes</td>
<td>The outcomes of matter-of-fact telling were neutral. The families did not view these disclosures as either positive or negative; the conversations simply occurred.</td>
</tr>
</tbody>
</table>

**Inconsistent telling: Not knowing what is going on** (p. 519)

<table>
<thead>
<tr>
<th>Description of Style</th>
<th>Parent(s) told adolescent(s) about the serious illness or impending death of the ill parent in ways that were changing and unpredictable. Inconsistent telling involved a mixture of not telling, telling very directly, telling practical information, delays in telling, and telling information that was not true.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Parent-Adolescent Interaction</th>
<th>The interactions between parents and adolescents in inconsistent telling are conflicted. The parents often misjudged what the adolescents wanted or needed to know about the ill parent. The adolescents were angry at their parents for how they handled disclosure.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outcomes</td>
<td>The outcomes of inconsistent telling were generally negative. Many adolescents expressed anger when they heard the “bad news” because they felt that they had received too much or not enough information.</td>
</tr>
</tbody>
</table>

Based on the important role of communication in supporting children's wellbeing as previously discussed, it could be argued that the information presented by Sheehan et al. could also apply to parents' communication with children aged six to twelve years. When made aware of the benefits of measured telling, parents could be encouraged to engage in conversation with their younger children about the situation that are measured developmentally. This would help children to know there is a genuineness to their thoughts and feelings especially with regard to...
what they have sensed in their gauging the non-verbal and the emotions of their parents. Children will have a developmental understanding of the reason for the changes in their parents and significant others (physically and emotionally). In addition, measured telling could create close transactions between parents and young children. Moreover, parents' knowledge of the benefits of measured telling has the potential to alleviate some of the factors associated with hesitancy or inability to talk with children as outlined in the following sub-section.

Factors influencing parents’ communication with children. Further research indicated that communication is often interrupted by parents not telling or withholding information because they fear information will create further distress for their children. This research provided insight into the factors which influence parents’ ability to communicate news regarding the parent’s advanced cancer. Not telling or withholding information is associated with the following: fear of distressing the children, a need to protect children, children’s developmental level would impede understanding, and a lack of agreement between parents about whether the children should be told (what, how and when) (Fearnley, 2012; Kennedy & Lloyd-Williams, 2009b; Sheehan et al., 2014; Turner et al., 2005; Walsh, Manuel, & Avis, 2005). Parents indicated that their reasons for telling their children of their declining condition and anticipated death included avoiding secrets, involving children, and doing what they feel is best for their children’s future (Kennedy & Lloyd-Williams, 2009b; Sheehan et al., 2014).

MacPherson (2005) conducted a retrospective study with nine bereaved parents in Scotland examining factors which influenced telling children that a parent is dying of terminal illness. The results of this qualitative study advanced the knowledge of how and when well parents/caregivers prepare their children. Specifically MacPherson noted the following factors:
The extent to which they themselves were able to face the reality and inevitability of death, their capacity to face and control their overwhelming and often paradoxical emotions and thoughts in order to carry on with the exacting daily responsibilities, and their previous experiences of death. (p. 122)

The interactions between the ill parent and well parent is an additional focus of research. At times, the wishes of the ill parent superseded in terms of whether, when and what the children were told. In such situations, the well parent often followed the lead of the ill parent until the imminence of death necessitated disclosure (Kennedy & Lloyd-Williams, 2009b). The preparedness of the children was captured by MacPherson in the following table:

<table>
<thead>
<tr>
<th>Table 3. Preparation of Children (MacPherson, 2005, p. 122)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Prepared</td>
</tr>
<tr>
<td>1. Neither able to talk about dying</td>
</tr>
<tr>
<td>2. Well parent able to talk; dying parent not able</td>
</tr>
<tr>
<td>3. Dying parent able to talk; well parent not able</td>
</tr>
<tr>
<td>4. Both able to talk about dying and preparing the children</td>
</tr>
</tbody>
</table>

**Role Reversal**

Role reversal and a felt need to care for both parents, in particular the well parent, was evidenced in the empirical research. Children in a study conducted by Beale et al. (2004) discussed taking on the role of caretaker for their ill parent. This finding was reiterated by Phillips and Lewis (2015). Through a qualitative inquiry of seven adolescents coping with a parent’s advanced cancer, the authors concluded, “Adolescents often struggle with role changes within the family due to the parent’s cancer, including role reversals in which they become the caregiver for their ill parent” (p. 852). Research by Rainville et al. (2012) also depicted this struggle experienced by adolescents as they indicated:
Adolescents, typically struggling for independence and attempting to form a separate identity, can experience feelings of conflict when developmentally driven desires to break away from the family clash with parental illness driven obligations of being available at home practically, physically, and emotionally. (p. 521)

Children who participated in the study conducted by Forrest et al. (2009) voiced a sense of empathy for fathers in addition to care-taking and role reversal in attempts to protect their fathers. Moreover, in a study by Heiney et al. (1997) on the effects of parental anxiety on children’s adjustment, the authors proposed that children may hide their true emotions to protect their parents. Furthermore, a child may need to portray a false self to protect his or her parents from further stress (Kennedy & Lloyd-Williams, 2009b). The sense of emotional responsibility, supporting and comforting parents, in addition to a profound need to be strong was reiterated in the work of Kennedy and Lloyd-Williams (2009a). The notion of false self will be discussed further in the theoretical framework in Chapter Three.

Turner (2004) provided evidence of the psychosocial impact of advanced breast cancer on families, and specifically on children. Turner noted an “erosion of those normalizing activities that promote optimism and a sense of competence in the face of adversity” (p. 61). At a time of great anxiety when children should have the support of adults to provide a sense of security, children may feel they need to emotionally support their parents, which could heighten distress.

Children’s Coping Strategies

Childhood presents children and adolescents with lived experiences that are typically filled with challenges, both welcome and unwelcome. Children navigate these challenges initially, when young, with significant support of parents or significant others. As children grow and cope with the challenges they encounter, their ability to navigate new challenges independently
increases. Additionally, with age children’s support with challenges stems beyond parents to friends and social supports. Advanced cancer presents children and adolescents with multiple, complex and emotionally laden challenges that can overwhelm their ability to cope. An understanding of the ability of children and adolescents to cope with the myriad of challenges they face was incorporated into this review of the empirical literature.

Research by Compas et al. (1996) focused on the coping strategies used by children and adolescents living with a parent diagnosed with cancer. The authors based their interviews on three coping strategies defined by Lazarus and Folkman (1988): problem-focused (trying to change aspects of the situation), emotion-focused (ways of coping with the emotions of the situation), and dual-focused (combination of both problem and emotion focused coping). Results indicated that children and adolescents rely primarily on emotion-focused strategies (such as avoidance) in addition to dual-focused strategies. Taking this further, Thastum et al. (2008) interviewed twenty-one children coping with a parent’s cancer to understand children’s coping based on their perceptions of their parents’ emotional states and coping, and parent-child communication. Thastum et al. clustered children’s descriptions into five strategies, “helping others, parentification, distraction, keeping it in the head, and wishful thinking” (p. 132).

Although children expressed a desire to talk about their emotions and the emotions of their parent(s) based on what they observed and felt, many children indicated this did not happen. The children who coped better felt their parents talked about emotions (their own and their children’s) in addition to coping. Thastum et al. therefore concluded, “Communication patterns and parental coping seemed to be highly related to the child’s coping repertoire” (p. 123).

Hilton and Gustavson (2002) provided further insight to coping of children and parents based on research by Brown (1992) of adolescents and parents with cancer. Incorporating
Brown’s theme of “shielding”, Hilton and Gustavson proposed the theme “being shielded”. According to the authors, “Shielding refers to how open or protective children were about their thoughts and feelings and how they protected themselves or opened themselves to others. Being shielded refers to what others did to open or protect the children from the situation and its stress” (2002, p. 199). In light of the intense emotions, uncertainty, and anticipatory loss experienced by children and parents, the research on shielding is understandable and directly applicable.

This research was extended in a study of interaction patterns between adolescents and their parents when a parent is dying from advanced cancer. Sheehan and Draucker (2011) provided insight into the ways families make the most of the time they have left, specifically outlining a four-stage process: “coming to know our time together is limited, spending more time together, extending our time together, and giving up our time together to end the suffering” (p. 1108).

Advanced cancer presents multiple, complex and emotionally laden challenges that can overwhelm children’s ability to cope. This parallels parents being overwhelmed, coping with their own worry and realization of the diagnosis, in addition to the need to protect their children. The research reinforces the importance of communication, measured telling, and sharing of thoughts and feelings to promote coping and the psychosocial well-being of children and parents.

**Positive Aspects**

Despite the myriad of complexities from advanced cancer, research is now providing insight to the positive aspects or outcomes as voiced by adolescents and parents. In a review of the research, Zaider et al. (2015) noted a “remarkable adaptation and resilience” demonstrated by families coping with terminal illness. Ku¨hne et al. (2013) also commented on adaptation and resilience of families facing impending death.
Spending more time together and cherishing that time while creating memories was a theme present in the limited research that incorporated positive aspects (Kennedy & Lloyd-Williams, 2009b; Phillips, 2014; Phillips and Lewis, 2015; Sheehan et al., 2011). Moreover, Kennedy and Lloyd-Williams (2009b) commented on positive outcomes as voiced by children. Children related the following as positives: “learning how to care for others, being prepared for adult life, and learning to appreciate their family” (p. 5). The authors provide further insight adding, “The most common positive aspect described was a sense of becoming closer to family members and learning to appreciate them, being grateful for what they have” (p. 5).

Phillips and Lewis (2015) noted the following positive outcomes which parents felt their children gained from the cancer experience: “increased independence, learning to prioritize, and improvements in relationships with family members” (p. 856). Positive aspects were also voiced by adolescents, themselves. “The parent’s cancer helped shape them, influenced their self-image, fostered their own maturity, and enriched their own perspective on life” (p. 854).

Despite the overwhelming, and at times insurmountable, fear, uncertainty and emotion faced by children and parents in the face of advanced cancer, the positive aspects voiced of the lived experiences speak to powerful resilience, individually and within the family.

**Summary of the Thematic Presentation of the Literature**

The literature provided insight into a variety of issues faced by children and parents when coping with advanced cancer of a parent. Table 4 outlines each theme in relation to the research questions as stated on page 16 (Chapter One).
### Table 4. Themes in the Empirical Research

<table>
<thead>
<tr>
<th>Themes in the Empirical Research</th>
<th>Research Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipatory Loss</td>
<td>RQ # 1, RQ # 2</td>
</tr>
<tr>
<td>Emotional Distress</td>
<td>RQ # 1, RQ # 2</td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td>RQ # 1</td>
</tr>
<tr>
<td>Parenting – The Dying Parent’s Experience</td>
<td>RQ # 1</td>
</tr>
<tr>
<td>Living with Uncertainty</td>
<td>RQ # 1, RQ # 2</td>
</tr>
<tr>
<td>Parents’ Perception</td>
<td>RQ # 2</td>
</tr>
<tr>
<td>Communication</td>
<td>RQ # 1, RQ # 2, RQ # 3</td>
</tr>
<tr>
<td>• Factors Influencing Parents’ Communication</td>
<td></td>
</tr>
<tr>
<td>Role Reversal</td>
<td>RQ # 1, RQ # 2</td>
</tr>
<tr>
<td>Children’s Coping Strategies</td>
<td>RQ # 2, RQ # 3</td>
</tr>
<tr>
<td>Positive Aspects</td>
<td>RQ # 1, RQ # 2</td>
</tr>
</tbody>
</table>

**Analysis of the Research Literature**

“How you collect data affects which phenomena you will see, how, where, and when you will view them, and what sense you will make of them” (Charmaz, 2006, p. 15). This comment highlights the importance of analyzing the literature to provide insight into the ways in which this research focus has been studied to inform understanding. The analysis will look specifically at the studies directly related to the focus of this doctoral research, and specifically, how the authors used their research methodologies to explore the issues of children and parents. Additionally, the research orientation of the authors will be included to bring awareness to the current extent of social work representation. It is of importance to also pay attention to what is
absent from the literature, what is not said. These gaps will give further rationale for this doctoral study. A summary of the strengths and limitations of the literature will conclude this section.

**Methodological Approaches of the Research Literature**

With regard to the methods used for the collection of data in the research reviewed, consistencies were evident. Most of the relevant studies reviewed used qualitative methods. Exploratory and descriptive in nature, “qualitative research allows researchers to get at the inner experience of participants, to determine how meanings are formed through and in culture, and to discover rather than test variables” (Corbin & Strauss, 2008, p. 12). Moreover, Thastum et al. (2008) contend that qualitative methods provide in-depth understanding of the subjective experiences of families coping with advanced cancer. An individual’s subjective experience can be explored through several qualitative research designs, gathering rich salient data. Of the research reviewed, the following designs were used: grounded theory (different methods of analyzing the data), phenomenology, and case study. Each approach represents a process through which images true to the participant’s story emerge (Creswell, 2007).

Grounded theory is an inductive methodology that enables theory to be developed from data (Corbin & Strauss, 2008). Kennedy and Lloyd-Williams (2009a, 2009b) conducted two studies using a medical orientation with the objective of developing an in-depth understanding of children and parents living with advanced cancer. In both studies, Kennedy and Lloyd-Williams recruited twelve families from a cancer centre, two hospices, 5GP practices, and a gynaecological oncology team in Liverpool, England (2009a, p. 2; 2009b, p. 150). The voices of eleven children eight to eighteen years, ten ill parents, and seven well parents were heard through semi-structured interviews. The specific research focus related to perceptions of children and their parents in regard to coping, life changes, communication needs, and barriers to accessing
support. Positive aspects also explored in the authors’ initial study (2009a) were of special interest for the current dissertation research. Providing space for the participants to give voice to what they feel is positive about their realities has been given little to no attention in the literature.

Constant comparison methods were used to analyze the data. The authors worked to include an in-depth discussion of the narratives of children and parents. Rather than providing their own summary of the results, specific and lengthy examples of commentary voiced by participants were highlighted enabling the participants’ truths to be present. The authors balanced the children’s perspectives with those of the parents, providing insight to the themes of coping, communication needs, and barriers to accessing support, as well as positive aspects.

Although the results of both studies advanced understanding of the themes indicated, it is important to look at what was not included. The meaning of the situation for children and parents was not discussed, outside the themes. Emotional security and parent/child relationships were also left out of the discussion. These missing aspects are key to developing an understanding of the experiences of children and parents, thereby providing validation for the doctoral inquiry.

Sheehan and Draucker (2011) also conducted a study utilizing grounded theory. Through a nursing orientation, the authors investigated the interactions between parents and adolescents when a parent is dying of cancer. Recruited from a hospice in Ohio, semi-structured interviews were conducted with nine parents living with advanced cancer, seven partners, and ten adolescents, twelve to eighteen years. Through a detailed analysis, Sheehan and Draucker distilled the data formulating a model delineated as a Psychosocial Problem: Not Having Enough Time Together and a Psychosocial Process: Making the Most of the Time We Have Left Together. This represents a unique way of providing insight into the experiences of adolescents and their parents, particularly as the focus was on interaction patterns.
However, the discussion was based on concrete tangible aspects such as adolescents doing things for a parent to help ease their suffering, or parents creating tangible pieces of their legacies which the adolescents can have in years to come. The absence of the emotional aspect of relationships is apparent: how the impending death of parents emotionally affected adolescents and parents; and the roles of attachment in supporting children emotionally, pre and post death.

As an extension of the previous study, the focus of a study by Sheehan et al. (2014) related to telling adolescents a parent is dying of cancer. Nursing and social work represented the orientation of the research team. The authors’ source of recruitment was a hospice in Ohio from which a sample of twenty-six participant families with children aged twelve to eighteen was drawn. The aim of the study was to “explore the complex and dynamic ways in which disclosure occurs when a parent is in hospice, in order to better understand how to assist parents with the difficult challenge of informing children that a parent is seriously ill and/or dying” (p. 513). Constant comparison methods were used for analyzing the data, with interesting results. Parents used four specific patterns to inform children of the impending death: measured telling, skirted telling, matter-of-fact telling, and inconsistent telling. The voices of adolescents and parents were directly represented in the authors’ discussion of the four communication patterns.

A strength of this article is that it provides professionals with information that will support parents in communicating with children about dying (specific to cancer but also terminal illness in general). It is also important to identify what is not included. As this study specifically focuses on communication, it provides a concrete discussion of what was said. However the construction of meaning, how parents and adolescents make meaning of the news, was not evident. More importantly, the discussion of the communication patterns was void of emotional aspects. How parents and adolescents coped with the threat to emotional security is a key piece of the
bidirectional relational focus which was again absent from the literature. The gaps in the studies by Sheehan and Draucker (2011) and Sheehan et al. (2014) give further justification for the current doctoral study.

A final study based on grounded theory was conducted by Phillips and Lewis (2015). Phillips’ research orientation is child life, while the research orientation of Lewis is health psychology. Through inductive content analysis, the aim of this study was to give voice to adolescents’ experiences of living with a parent who was dying from advanced cancer. The sample involved seven adolescents, eleven to fifteen years, representing six families. Phillips and Lewis set out clear details of the inductive analysis completed, enabling the voices of the participants to be heard and understood. The authors identified a core construct labeled Weaving a Normal Life with Cancer, from which five themes were developed: “feeling the weight of the world on my shoulders; cancer changes everything; confronting or getting away from the cancer; talking about it; and cancer was a positive for me … it taught me” (p. 851).

This study holds particular strength and relevance to what was said. The authors bring direct narrative accounts to the discussion. More importantly, they give clear voice to the emotionality of the lived experiences of the adolescents. Anxiety for the future, emotional insecurity and depth of sadness were highlighted. This is the first study to give validation to the depth of the emotional experience. Additionally, the authors give space for positive aspects which, as previously mentioned, have traditionally been missing from the discussion.

However, the discussion ends there. Only the voices of adolescents were represented. The significance of the effect on the interpersonal relationship for adolescents and parents was not discussed. Although the authors stated, “This study reveals the coping strategies adolescents and their families use to create normalcy in their lives despite the cancer” (p.852), adolescents were
their only focus. There was no discussion about whether the parents gave voice to similar concerns regarding the emotionality of the situation. A key aspect portrayed in the review of the literature related to the fact that parents’ perceptions of their children’s experiences is often very different from their children’s. Perhaps in separate interviews with parents, questions could be asked that are related to this aspect, strengthening the study. That being said, this study does advance the understanding of emotional issues faced by adolescents. Moreover, the authors opened up the need for further research drawing on the lived experiences of children.

Phenomenology involves an “interpretive process in which the researcher makes an interpretation of the meaning of the lived experiences” (Creswell, 2007, p. 59). This was the basis for research Bugge, Helseth and Darbyshire (2008) conducted through a nursing orientation. The purpose of the study was to evaluate a support program for children in Oslo, Norway, coping with a parent living with advanced cancer. It was not clear whether any of the researchers were involved in running the support group. Semi-structured interviews with twelve children (six to sixteen years) were conducted. Kvale’s (1996) guidelines for qualitative analysis were used for the data analysis. Results portray the emotional reaction of children to their parent’s impending death, primarily that of fear. Children’s sense of belonging in the group and the reassurance that other children think and feel as they do were also discussed. Additionally, some short narrative commentary by a few of the participants was included, giving voice to the children’s lived experiences. However, the discussion would be richer if it included how children make meaning of their experiences, in addition to the relational aspects of attachment and intersubjectivity. That being said, this study addressed the important aspect of developmentally appropriate community supports for children coping with a parent’s impending death.
A study of significance was conducted by Christ (2000) using a “collective case study analysis” (p. 43). From the orientation of social work situated in New York, the manner in which this study was conducted was unique. It focused on a longitudinal qualitative inquiry spanning six months prior to, and fourteen months following, a parent’s death from cancer. Christ felt it necessary to understand the pre-death experiences of children and parents to facilitate positive outcomes post death. This gives further validation for this doctoral study. The sample size for Christ’s study was larger than the other studies reviewed, 88 families (157 children, three to seventeen years). The children were interviewed at successive periods. Through rigorous data analysis, a developmental comparison of children within each age group was outlined, followed by a comparison between age groups.

Strengths of the study include its sample size and duration. This longitudinal study enabled Christ to develop an in-depth understanding of the relational focus, alongside the emotional insecurity posed by the loss of key relationships for the children involved. Christ’s study generated a wealth of information which advanced and strengthened the knowledge base, particularly in the following areas: how children developmentally make meaning of a parent’s terminal status; questions asked of the parent(s); behaviours as indicated by the parent(s); together with an understanding of the death, bereavement, and reconstitution (2000). Christ was able to illuminate the meaning of the dying time for children through interpersonal relationships, and advocated for further research regarding this sensitive time.

Beale et al. (2004) also used a case study design with a sample of twenty-eight children, three to eighteen years to determine the incidence and relevance of eleven factors: seeking reassurance; becoming a caretaker, inability to separate from parent, anger about feeling abandoned, despair, guilt, discipline problems, aggressive behavior, denial, blame of others, and
fear for the child’s own health. The research orientations of the authors were medical (child psychiatry and palliative care) and nursing. The basis of data collection was semi-structured interviews with children. The authors provided few details regarding data analysis, only stating, “Data are reported using descriptive statistics” (p. 389). The findings were presented as three case studies providing indication of the participants’ thoughts and feelings. As with the previous studies in this analysis, the authors advanced the perspective of children, especially with regard to emotions. However, the aspects of the developmental perspective, emotional insecurity and parent child relationships, were not incorporated, further contributing to a void in understanding.

In addition to the qualitative research discussed, one study with relevance to adolescents and parents with advanced cancer used quantitative methods, an explanatory cross-sectional study conducted by Rainville et al. (2012). The lead author completed the study as part of the MSW degree program at Laval University. The study’s aim was to determine “to what extent adolescents who have a parent with advanced cancer experience more psychological distress than adolescents in the general population” (p. 523). Twenty-eight adolescents, twelve to eighteen years, were recruited from three tertiary care hospitals in Quebec City. The participants completed the Indice de d´etresse psychologique de Sant´e Qu´ebec (IDPSQ-14), a self-report multidimensional index of four dimensions (depressive state, anxious state, cognitive problems, and irritability) (p. 523). Parametric tests were used to compare the psychological distress of the participants with a comparison sample representative of Quebec’s adolescent population.

The primary conclusion drawn from this research validated the hypothesis that “adolescents living with a parent with advanced cancer have higher levels of psychological distress, than adolescents in the general population” (p. 523). This result is fitting with the role of emotional distress discussed earlier in this chapter. Although the authors’ research validated
conclusions of the literature reviewed, the sample was small for a quantitative study. Additionally, the authors only incorporated, and relied on, one measure, the IDPSQ-14. Utilizing other measures or combining this measure with qualitative interviews which bring in the voices of the participants would strengthen the research methods and study as a whole.

**Strengths and Limitations of the Research Literature**

Important issues related to children and families coping with advanced cancer and impending loss were illuminated in the research. Despite the critiques indicated in the analysis, the authors were successful in focusing the research lens on some of the myriad of issues faced by children and parents living with, and dying from, advanced cancer. The distress felt by parents and children was articulated in some studies, providing the validation for this doctoral research. Additionally, the need for open communication was found as a critical factor in children’s well-being and ability to cope. The parent/child relational aspect was represented in some of the later studies. Moreover, two studies provided a developmental perspective to children’s meaning making. Two studies brought positive aspects to the discussion. Finally, the research begins to shed light on the phenomenon of the lived experiences of children and parents making the most of their time together while anticipating the loss of a parent.

Limitations of the studies reviewed are important to discuss as they represent pathways for future research. The primary limitation is the meagreness of research directly related to the lived experiences of children and parents who are living with, and dying from, advanced cancer. Additionally, the conclusions of the studies indicate the need for further research to advance the understanding. Another key limitation involved the low representation by social work. Although as discussed in Chapter One, social workers play an important role in oncology and palliative care, research from this perspective is minimal. The lack of a developmental perspective is
another limitation. Although the studies focus on a wide age range, spanning three to eighteen years, the discussion of children was very general. Adolescents think and feel very differently from preschool children. Further limitations focus on what was specifically missing from the studies as indicated in the critical analysis.

**Summary of the Literature Review and Analysis**

This synthesis and analysis of the literature situated and contextualized the experiences of children and families coping with a parent living with, and dying from, advanced cancer. Although several issues faced by children and families coping with end stage cancer were woven through the research, the critical gaps and meagreness of the literature are evident. The understanding of this sensitive time for children and parents is murky at best. This doctoral research will address some of those gaps to provide greater clarity to the understanding.

Particularly relevant is the analogy referred to as “death’s waiting room” (Buchwald et al., 2012). More attention must be given to understand what this room represents for children and parents. Key to this is the development of insight to the loss of the attachment relationship with the dying parent, and the emotional support provided by the dying parent and the well parent. There is a need for more knowledge of the parent/child relationships in relation to advanced cancer. This provides further justification for this doctoral research.

Also absent from the literature is material related to assisting social workers and allied professionals with the pre-death phase and the threat to emotional security posed by the loss of the attachment relationship. As Bugge et al. noted, “Children’s reactions and coping when one of their parents has cancer merits greater attention from health professionals” (2008, p. 426). Although social work was represented by some authors, it was the minority as has been
discussed. Early intervention may lead to fewer issues developmentally and enhance psychosocial well-being, resulting potentially in lower health costs.

Additionally, an aim of the current doctoral research is to inform interventions involving the parents and children. Such interventions would support the parents’ understanding of the impending emotional loss for children. More specifically, such interventions would assist well parents in understanding their own attachment relationship with their children, acting as a buffer in this time of loss. Supporting social work education to facilitate short- and long-term outcomes for children and parents provides further validation for the importance of this doctoral research.

Children’s vulnerabilities, together with the potential long-term psychosocial risks to development, are case enough for the critical need for research. It is important to comprehend the meaning children and parents/caregivers ascribe to advanced cancer, and to the anticipated death of the parent and emotional anchor. Thus, this present investigation of this sensitive time of anticipatory loss for children and parents is warranted.
Chapter Three
Theoretical Framework

Originating from the Greek word *theoria*, theory can be equated with thinking about or considering a subject. This chapter presents the theoretical framework which provided a lens for thinking about parent/child relationships and the uncertainties of advanced cancer and anticipatory loss. With the complexities of family situations and advanced cancer, it was important that the theoretical lens be multifaceted to provide depth and breadth to the comprehensive understanding. Therefore, the framework outlined in the following sections moves from general to specific. As this doctoral study encompassed middle childhood (six to eleven years) and adolescence (twelve to eighteen years), the initial section of this chapter will focus on development to provide a general context related to children. This context must be inclusive of individual diversity, “interwoven with the social and cultural worlds in which children are raised” (Nolan & Raban, 2014, p. 10). Therefore, the information included for each age group should be considered as general, rather than universal.

The theoretical framework was situated in Social Constructivism, and Sociocultural Theory (Vygotsky) to offer insight into the process of how children make meaning of significant life events. This was followed with the relational theories, attachment and intersubjectivity. Both theories provided a distinct lens to better understand parent/child relationships. A discussion of the neurobiological underpinnings of these relational theories follows to further the insight. Situating each section within the context of children and parents coping with advanced cancer and anticipatory loss enabled clarity and comprehensive insight into the complexities of this compelling issue. Finally this chapter concludes with a theoretical model grounded in this framework.
Potential Developmental Gains of Children Six to Eighteen Years

As the focus of this doctoral study was on middle childhood and adolescence, a summary of general developmental gains for each age group has been provided. This discussion of development concludes with an overview of children’s understanding of dying and death. The aspects outlined in this section must be viewed as fluid, rather than fixed. Development is not universal and, with that, this discussion is meant to provide a general outline of child development. Focusing on individual differences within age groups, in addition to differences across age groups, is also an integral aspect to child development. Bernhard and Gonzalez-Mena (2000) noted, “Understanding development needs to encompass a new, and perhaps a more relevant, understanding of what comprises ‘normal’ development and expectations” (p. 253). Individual diversity, culture, and experiences play significant roles in how children make sense of their world. Rogoff reiterated this contending, “All children grow as members of cultural communities so understanding how childhood is supported, constrained and constructed in any community is part of understanding child development” (2003, p. 45).

**Middle childhood (6 to 11 years).** Middle childhood generally represents a time of expanding development (Allen & Marotz, 2003; Beck, 2008; Papalia, Olds & Feldman, 2009; Santrock, 2013). As language development is virtually complete, children in this stage may be more able to articulate their thoughts and feelings (Beck, 2008). Most children have an increased ability to think logically, reverse thoughts, and understand more complex concepts. Children at this age are generally incapable, however, of understanding the world through an adult’s lens (Beck, 2008; Santrock, 2013). Intangible concepts such as dying and death are difficult for them to grasp and therefore may become a source of great anxiety for children.
Children can become more adept at demonstrating empathy and understanding the perspective of others (Allen & Marotz, 2003). This enables an understanding of what their parent’s illness and impending loss means to the well parent. Additionally, children are better able to understand their emotions, and express their feelings. Strong emotions, however, may overwhelm children, leading them to seek the support of trusted adults. Crises, such as the impending death of a parent, may evoke internalizing or externalizing of behaviour by children during this stage (Christ, 2000; Webb, 2007). Moreover, aspects such as changes in routine, witnessing their parents’ deteriorating health, and the immense associated uncertainty may result in some children experiencing separation anxiety from their parents, despite having been previously comfortable being apart from them (Beale et al., 2004; Christ, 2000; Webb, 2005).

**Adolescence (twelve to eighteen years).** Adolescence can represent “one of the critical transitions in the life span and is characterized by a tremendous pace in growth and change that is second only to that of infancy” (WHO, 2016, para 1). Complex needs stemming from emerging identity, autonomy, socialization, and responsibility may fill the adolescent world. “Many teenagers feel as if they are juggling two lives simultaneously: the leftover kid’s and the emerging adult’s” (Fiera, 2012, p. 36). Variance exists regarding the defining age of adolescence, examples of which include:

- ten to nineteen years (Canadian Paediatric Society, 2016, para. 3; WHO, 2016, para. 1);
- thirteen to nineteen years (Public Health Agency of Canada, 2010);
- fifteen to twenty-four years (United Nations Secretariat, 2013);

For the purposes of this research, the age range of adolescence was twelve to eighteen years.

Adolescents are generally better able to think abstractly. As a result, adolescents are generally more aware of the short term and long term implications of losing someone, and may project into the future to a life without the person (Phillips, 2014). Due to this realization, some
adolescents may experience increased reactions to the anticipated, and actual, loss of their parent (Arkitel, 2015; Christ, 2000; Christ & Christ, 2006; Webb, 2005). An increase in moral
development, existential thinking, and sense of the ideal world can parallel the shift in cognitive
thinking by this time. The unfairness of the world may overwhelm an adolescent as it does not
measure up to what is ideal (Arnett, 2013; Beck, 2008). This sense of unfairness can encompass
significant life events such as illness, dying and death. Adolescents may feel deeply, and
anticipating loss of a parent can lead to heightened vulnerability and distress (Phillips & Lewis,
2015; Spira & Kenemore, 2000). Identity and autonomy are considered to be two main shifts in
adolescent development (Siegel, 2014). Influences such as the anticipated and actual loss of a
parent can shape a teenager’s emerging identity (Fiera, 2012). Often a teenager may feel he/she
is the only person in their social circle facing the sadness of loss, creating a sense of difference or
otherness for them. Significant life events in a family (such as terminal illness, dying and death)
can shape many of an adolescent’s decisions, choices and attitudes (Arnett, 2013; Phillips &
Lewis, 2015; Spira & Kenemore, 2000).

**Children’s understanding of dying and death.** Children’s understanding of dying and
death is important to consider. This understanding may be facilitated, or impeded, by interactions
between development, individual meaning making, and interpersonal relationships, social and
cultural aspects (Christ, 2000; Nolan & Raban, 2014; Slaughter, 2005; Webb, 2005; Worden,
1996). Children often grieve as they grow. Their ability to make sense of the anticipated and
actual loss may be intertwined with developmental unfolding. They can potentially revisit the
pre- and post-death periods with each life transition in an attempt to make sense of the loss and
circumstances. Speece (1995) proposed that “age is the most common variable to be examined in
relation to children's concepts of death” (para. 15).
Social Constructivism and Sociocultural Theory

“All knowers are constructing reality by living it” (Koro-Ljungberg, 2008, p. 986).

Truths and realities vary with lived experience. Granvold (2008) commented, “Meanings are socially embedded and are constructed out of life experience” (p. 401). Reality is constructed through social interactions, influenced by language and culture, and reflective of diverse understandings. These views are relevant to terminal illness and impending death. To capture diverse lived experience, this theoretical framework focused on meaning making of the uncertainty of advanced cancer, and the dying time through a social constructivist lens.

Social constructivism. The epistemological position of social constructivism furthered the understanding of advanced cancer and anticipatory loss. Social constructivism is based on the premise that knowledge and understanding is constructed, and co-constructed, through experience and interpersonal interactions within social, historical, and cultural contexts (Gillies & Neinmeyer, 2006). Social constructivism requires two or more active participants as individuals cannot effectively construct meaning in isolation (De Mol & Buysse, 2008; Gergen, 1995; Granvold, 2008). Through a social constructivist lens, knowledge is co-created between a joining of minds, not an isolated phenomenon in participants’ own minds (Gergen, 1995).

Proponents of social constructivism contend that knowledge construction and shared meaning can be influenced by factors such as culture and perspective (Garneau & Pepin, 2015; Gergen, 1995; Gillies & Neinmeyer, 2006). Viewing culture as the product of social constructions, Carpenter-Song, Nordquest-Schwallie, and Longhofer argued that “culture is a dynamic relational process of shared meanings that originate in the interactions between individuals” (2007, p. 1364). Culture is an integral part of illness and impending loss.
Differing perspectives can influence construction of knowledge and the manner in which meaning is created. This aspect is fitting when working with children as it is important to recognize children as a diverse social group and active agents who have a keen desire to make sense of their worlds. Knapp indicated, “Work in parent-child relations reflects a growing recognition of the need to theorize the child as an active agent (1999, p. 53). Construction of knowledge with a trusted adult facilitates a child’s understanding of stressful situations. A social constructivist perspective emphasizes interactive relationship in which children and parents are thinking subjects, where meanings are co-constructed (De Mol & Buysse, 2008).

**Sociocultural theory.** “The child is a determiner not determined (Vygotsky, 1978). Vygotsky’s sociocultural theory (1978) holds significance for understanding child development, especially children’s knowledge construction. This theory advances the importance of social interactions, language, and culture as key facilitators of a child’s meaning making and knowledge construction (Bordova & Leong, 2007). An important tenet of Vygotsky’s work pertains to his view that knowledge does not solely pertain to cognitive aspects, but to psychosocial aspects as well.

**Intra and intermental dialogue.** Vygotsky (1978) contended that learning occurs through language and dialogue. In the progression of co-construction of knowledge, dialogue is initially intermental, situated between the adult and child. This is extended to a child’s meaning making through internal or intramental dialogue. Knowledge and meaning making occur both relationally through social interactions (parent/child relationships for example) and through reiteration in the child’s mind.

**Scaffolding.** Another construct important to the process of facilitating a child’s understanding is that of scaffolding. This pertains to the support provided by others (parents or
significant adults) enabling a child to build on prior knowledge and internalize new information. The needs of the child, together with the nature and newness of the knowledge or event, determine the degree of support provided. The adult provides considerable support with new or complex situations or knowledge which challenges the child’s current developmental capabilities. As the child’s level of understanding increases, the scaffolding lessens. The child is then able to use this knowledge as a reference point for future experiences.

**More knowledgeable other.** The concept of the more knowledgeable other (MKO) was developed by Vygotsky (1978) with relevance to adult/child relationships. Through a social constructivism lens, the MKO is an individual in the child’s world who has a greater understanding of a situation. The role of the MKO is to facilitate and scaffold a child’s developmental gains. Typically the MKO is an adult in the child’s world (parent or teacher). Peers could represent this role also (peer based learning or support groups).

**Zone of proximal distance.** Finally, Vygotsky referred to the space between a child’s current level of development and gains in development that a child is capable of attaining with scaffolding as the zone of proximal distance (ZPD). Vygotsky stated the ZPD was “the distance between the actual developmental level as determined by independent problem solving and the level of potential development as determined through problem solving under adult guidance, or in collaboration with more capable peers” (1978, p. 86). By recognizing a child’s ZPD, strategies can be geared specifically to a child’s developmental abilities.

**Situating Social Constructivism and Sociocultural Theory in Advanced Cancer and Anticipatory Loss**

As there are no truths to dying and death, a social constructivist lens will facilitate inclusion of difference to provide richness in understanding the experiences of children and parents/caregivers at this sensitive time. Social relationships, particularly parent/child, are
integral to meaning making. Social constructivism holds relevance to children’s ability to make sense of what is uncertain or scary, such as impending loss. Co-construction of meaning enables parents and children to be active agents.

Vygotsky’s sociocultural theory provides insight into children’s meaning making and needs. The importance of considering a child as a determiner, not determined, supports the inclusion of children in the dying time. Children are knowers of their worlds and adults have much to learn from them. Adults in the child’s world represent more knowledgeable others (MKOs) providing support. Communication and parental perceptions are crucial aspects in a child’s psychosocial needs, as indicated in Chapter Two. Intermalent and intramental dialogue also hold relevance. Developmentally appropriate communication will enable the parent(s) and child to discuss thoughts and feelings about cancer, the ill parent and impending death, intermental dialogue. Through inner speech, the child will make further meaning of the situation, intramental dialogue. Scaffolding enables construction of meaning of the family’s shared experience. A scaffold of appropriate support based on the child’s age and life experience can facilitate the child’s ability to understand and cope. Finally, the zone of proximal distance (ZPD) can be useful for social workers when developing psychosocial supports for children. Situating such interventions within the child’s developmental grasp will better enable positive outcomes.

The essence of individual realities and the social construction of knowledge provided a foundation for this doctoral research. The incorporation of the sociocultural theory provided a deeper understanding of children’s knowledge construction. Together with the relational theories to be discussed in the following section, these perspectives scaffold the issues of living with the uncertainty of advanced cancer and the dying time.
Relational Theories

“Human beings understand one another intimately, and at many levels” (Trevarthen, 2010, p. 5). The emotional aspects of parent/child relationships pertain to the intimate understanding about which Trevarthen speaks. To develop a comprehensive understanding of the lived experience of children and their parents coping with this time of uncertainty, a theoretical framework incorporating the relational theories of attachment and intersubjectivity was relevant. Attachment and intersubjectivity have been theorized as two separate, but complementary, motivational systems vital to human development and relationships (Stern, 2004; Trevarthen & Aitkens, 2001). As Stern stated, “Attachment keeps people close so that intersubjectivity can develop or deepen, and intersubjectivity creates conditions that are conducive to forming attachments” (2004, p. 102). These relational theories may reveal reasons for children’s struggles during this time of significant distress. An overview of each theory is presented. Both theories will then be situated within the context of this compelling issue, advancing the understanding.

**Attachment theory.** Attachment has been the subject of extensive research providing insight into parent/child relationship, adult relationships, and more recently, psychotherapy. Initiated by the seminal work of Bowlby (1969, 1973, 1982), attachment theory is grounded in evolution, psychology, and neuroscience. It represents an integral facet of nature which humans share with other species. Ground mammals run to hide in a hole when they are scared, however humans run to a person (Sroufe, 2011). Attachment has a key role in the survival of humans, brain development, affect regulation and interpersonal relationships. From cradle to grave, an individual’s basic sense of safety comes through connections with significant others.

Attachment is not a trait of the parent or child. It is the quality of the inter-dependent, bidirectional relationship between them. Schore (2001) argued that attachment represents the
biological attunement and synchronicity between the brains of the adult and child. A child is an active partner in the dance of attachment as the adult must learn to read and respond to the child’s cues, or bids for emotional connection. A primary tenet of attachment theory is that all infants develop attachment relationships (Ainsworth, 1989; Bowlby, 1969, 1973, 1982). Sroufe (2011) reiterated this, stating that even infants who are mistreated are attached. He added that it is the quality or nature of both the adult’s responsiveness and the infant’s felt security in the attachment relationship that is different. O’Connor and Byrne summarize the importance of attachment across the life span noting, “Attachment relationships are important from cradle to grave; but how they are expressed, with whom and under what circumstances naturally changes from cradle to grave” (2007, p. 188).

**Attachment figure.** Bowlby conceptualized attachment as an adaptive function in which humans, especially infants, need a warm, intimate and continuous relationship with an attachment figure. This attachment figure, or emotional anchor, meets emotional needs especially in the face of uncertainty or adversity. Ainsworth (1989) proposed that the attachment relationship is an enduring, emotional bond a child forms with a particular attachment figure who provides the child with security and comfort. Initial attachment research focused on the primary attachment figure, an adult preferred by the infant to consistently meet emotional needs.

With optimal development and increased experience in an expanding world, the need to have an attachment figure in close physical proximity may decrease. The role of an attachment figure in the mind of the child may move to an internal knowledge that the emotional caregiver will be available if needed. Availability can be seen as “a function of the degree to which there is open communication between the child and the attachment figure, the attachment figure is physically accessible, and the figure is responsive to the child’s bids for help” (Kerns et al.,
During times of distress, children may seek physical closeness with attachment figures, needing physical and emotional availability (Cassidy & Shaver, 1999; Dwyer, 2005; Kerns & Richardson, 2005; Moretti & Peled, 2004).

Although the role of a primary attachment figure remains an integral part of attachment, recent research has focused on the role of multiple attachment figures (Cassidy & Shaver, 1999; Dwyer, 2005; Hart, 2010; Mayseless, 2005; Sroufe, 2011). With aspects such as culture, diversity of family structure, shared parental leave, and an increased need for formal and informal child care arrangements, children may develop attachment relationships with more than one adult. Moreover, Mayseless (2005) contended that children may have different attachment figures in different contexts rather than one attachment figure for all contexts.

For the purposes of this doctoral research and dissertation, the term attachment figure will refer to a parent or adult who represents a source of emotional security to a child. This can be a child’s mother or father (biological, step or adoptive). It is the anticipated, and actual loss, of such an attachment figure and the emotional security that is the focus of this research. It is important to note that with each of the families who participated in the study, the attachment figure was a biological parent.

**Attachment security.** Attachment security is a strong and pervasive need maintained by the child’s confidence and trust in the availability and responsiveness of an attachment figure during times of distress (Schore, 2001; Tronick, 2005). This sense of security extends to relationships across the life span, shifting in emphasis of need (Hughes, 2007). With lived experience and maturity, children develop a larger repertoire of attachment behaviors to gain emotional proximity to attachment figures, moving from physical proximity. Ainsworth (1989) contended that the attachment system is highly responsive to and activated by two main events: (1) the
presence of potential danger in which an attachment figure provides a safe haven; (2) a threat to the accessibility or availability of an attachment figure, representing a secure base. Stern captured the importance of an attachment figure’s role noting, “the choreography of parental behaviours is the raw material from the outside world with which the infant begins to construct his knowledge and experience of all things human” (2000, p. 23).

Emotional provisioning, supporting the development of emotional regulation, is integral to attachment and parent/child relationships (Hart, 2011). Infants and young children have difficulty coping with strong emotions (both of self and others). As a result, an attachment figure often lends him/herself emotionally to the child, providing an anchor of trust guiding the child through distressing situations. This has been equated to emotional holding and containing (Hughes, 2007; Schore, 2001; Tronick, 2005). With consistent emotional provisioning, a child develops the capacity for emotional regulation. Emotional regulation is critical for future relationships, and coping with emotionally charged life experiences. Research has indicated that emotional regulation is mediated by cultural meaning systems (Butler, Lee, & Gross 2007; Ford & Mauss, 2015; Matsumoto, Yoo, & Nakagawa, 2008). Kim and Sasaki (2012) noted, “The larger cultural context can provide guidelines or expectations about social interactions that consequently affect the way people regulate their emotions” (p. 866).

**Attachment behaviour.** Active across the life span, the attachment system initiates attachment behaviors aimed to maintain proximity to, and communication with, an attachment figure ensuring emotional security (Bowlby, 1973; Cassidy & Shaver, 1999; Hughes, 2007, 2011; Johnson, 2004). When separated from an attachment figure, attachment behaviours for young children take the form of protesting, withdrawal or premature self-reliance. They are indicative of the child’s agentic influence to maintain safety/security in the parent/child
In secure relationships, the parent or emotional caregiver responds in a consistent and sensitive manner to the child’s emotional cues of distress, helping the child to regain a sense of emotional security. Consistent, sensitive responses disarm the attachment system and calm attachment behaviours (Sroufe, 2011). The term attachment rupture or injury has been used to describe the situation when an individual’s attachment or emotional security is threatened. This can have negative consequences to a child or adult relationship, particularly if the ruptures are extensive or frequent (Johnson & Whiffen, 2005; Tronick, 2005, 2007).

**Cross-cultural aspects of attachment.** Although attachment relationships are universal, attachment beliefs and practices differ around the world (St. Joseph's Women's Health Centre, n.d.). Cross-cultural aspects of attachment have been the focus of research to determine the relevance of this theory (Posada et al., 1995; Rothbaum, et al., 2000; Waters & Cummings, 2000). Research has been conducted along two lines: (1) maternal [parental] sensitivity or caregiving behaviour (responsiveness to an infant); and (2) attachment behaviour (actions by an infant experiencing threats to safety). Conclusions of this research indicated that need for emotional security and the safe haven/secure base in parent/child relationships transcends cultures (Posada et al., 1995; van Ijzendoorn & Sagi, 1999; Waters & Cummings, 2000).

**Theory of intersubjectivity.** “I know that you know that I know. I feel that you feel that I feel” (Stern, 2004, p. 75). Beginning in infancy, intersubjectivity can be seen as a relational process of joining together in emotional experiences, sharing of subjective states, and bidirectional agentic influence. As with attachment, intersubjectivity is a system of motivation that is essential for survival. Lyons-Ruth argued that “the unique capacities of the human infant for intersubjective exchange with others sets human attachment apart from other mammals” (2003, p. 5). This process sets the foundation for the development of self, formation of
interpersonal relationships, co-regulation of affect, and co-construction of meaning across the lifespan.

Theorists have studied intersubjectivity as it relates to psychoanalysis, focusing on the relational process between therapist and client (Lyons-Ruth, 1999, 2003; Stolorow, Atwood & Brandchaft, 1994; Stolorow, Brandchaft & Atwood, 1987). A consensus of these authors is that moments of meeting or authentic intersubjective connection with a therapist become pivotal points of change for clients. Leading theorists have contributed considerable theoretical works which provide an in-depth understanding of parent/child relationships, termed innate intersubjectivity (Beebe & Lachman, 2002; Stern, 2004; Tronick, 2005, 2007). According to these authors infants are born with awareness of, and receptivity to, subjective states of others (specifically parents). Moreover, through moments of meeting in which parent and child are emotionally attuned, each is changed by, and changes, the other. Known as bidirectional agentic influence (Kuczynski, 2003), this will be expanded on in the ensuing paragraphs. As this doctoral research focuses on children’s psychosocial needs and parent/child relationships, in addition to appropriate therapeutic support, both forms of intersubjectivity are of relevance.

With respect to the emergence of intersubjectivity, Stern (1985) indicated that the capacity for innate intersubjectivity is present from birth stating, “Moments of meeting the baby’s smile can immediately be put to use to maintain or reward the mother’s attention and share her pleasure” (1985, p. 124). Trevarthen (2010) discussed primary and secondary intersubjectivity. Primary intersubjectivity corresponds to the infant learning about emotional communication through imitation, and learning that he can have an effect on others to have needs met. Secondary intersubjectivity occurs by seven months of age when the infant is better able to emotionally attune to others. This is a time when joint attention and a psychological closeness begins.
Secondary intersubjectivity is present throughout life and characterizes parent/child and adult/adult relationships. Beebe, Knoblauch, Rustin, and Sorter, (2005, p. 27) outlined a developmental trajectory for intersubjectivity across the lifespan as:

- Infants are capable of “knowing”
- Toddlers are capable of conceptualizing “I know that I know”
- 5 year olds are capable of conceptualizing “I know that you know”
- Adults are capable of conceptualizing “I know that you know that I know”

Furthermore, intersubjectivity holds relevance for the research design and methodology selected for this doctoral study, interpretive hermeneutic phenomenology and the shared, overlapping and relational nature of individuals’ engagement in the world (Heidegger, 1962). This will be outlined in Chapter Four, Research Design and Methodology.

**The intersubjective space.** The intersubjective space exists in relationships such as parent/child, adult partner, or therapist/client. It is the space between the perceiver and the perceived (Madison, 2001). Through the intersubjective space there is a “psychological overlap between individuals and a flowing together of conscious and unconscious emotional currents” (Balbernie, 2007, p. 308). “Moments of meeting” occur in this space (Hughes, 2007). Hughes added that in this space parent/caregiver and child are cognitively and affective present, or in sync. Dyadic communication (verbal/nonverbal), attention, and attunement are critical facets of this space. Additionally explicit, conscious and implicit, non-conscious forms of information processing are integral facets of intersubjective relationships (Beebe et al., 2005; Lyons-Ruth, 1999; Schore & Schore, 2008; Stern, 2004).

Hart proposes a conceptualization of the intersubjective space, or moments of meeting in parent (caregiver)/child relationships (2011, p. 4), which has been depicted in Figure 2 on the following page.
Figure 2. The Intersubjective Space

This conceptualization provides visual insight into the contributions of both parent/caregiver and child to intersubjectivity. The intersubjective space encompasses the middle ground between parent/caregiver and child where implicit/explicit, conscious/unconscious, and verbal/non-verbal transactions occur. In optimal circumstances, such transactions result in a co-regulation of affect and co-construction of meaning; a true sense of felt security.

**Attunement.** Emotions are an integral part of interpersonal relationships. “Emotions automatically provide organisms with survival-oriented behaviours” (Damasio, 1999, p. 56). Individuals, especially children, have a strong need to feel “felt”, to know that someone acknowledges, understands, and responds sensitively to their feelings. It is through feeling felt that children learn to understand and feel the emotions of others. Sharing emotions or affective attunement is essential for secure attachment, and for the ability to relate to significant others in the intersubjective space. Stern (2000) conceptualized the reciprocal nature of affective attunement as interaffectivity, the capacity to put oneself in another’s emotional shoes. Additionally, the parent/caregiver has a vital role in acknowledging, understanding, and empathically responding to the emotions of a child, in turn supporting the child’s increasing ability to attune and respond reciprocally to the emotions of his/her caregiver(s) and others.

**Misattunement.** Although intersubjectivity and attachment are based on consistent and sensitive responses to a person’s emotional needs, being able to do so every time the person is in
distress is not possible. The result in misattunement, “The rhythm of attunement, misattunement, and re-attunement constitutes the music of human relationships” (Cozolino, 2006, p. 49).

Through empirical research, Tronick concluded that mothers misattune 65% of the time (2005, 2007). Misattunement (rupture) and re-attunement (repair) facilitate the child’s ability to weather mistakes and breaks in relationships. Rupture and repair foster the development of trust, emotional or affect regulation, and resilience. The child gains a visceral assurance that if things go wrong (relational stress), they can be set right. An equally important function of misattunement is to facilitate the development of the child’s ability to distinguish and differentiate him/herself from his caregiver, facilitating positive self-image.

**Implicit and explicit knowing.** Implicit knowing refers to things that an individual knows or does automatically without conscious awareness. Stern theorized implicit knowing as “non-symbolic, nonverbal procedural, and unconscious” (2004, p. 113). It is a vital facet of interpersonal relationships. Throughout life, implicit knowing continues to shape interpersonal relationships. The theoretical literature has expanded this form of knowing to include implicit relational knowing, seen as a “ways of being with another;” knowing how to be in relationships (Beebe et al., 2005; Stern, 2000, 2004).

Explicit knowing refers to what an individual knows, remembers or does that is brought to consciousness such as recalling information and events. Stern theorized explicit knowing as “symbolic verbalizable, declarable capable of being narrated and reflectively conscious” (2004, p. 113). Explicit knowing shapes autobiographical memory, and is a vital facet of attachment and intersubjectivity; consciously knowing how to have emotional needs met (Hughes, 2007).

**Joint attention, myth of the isolated mind, and changing with the other.** Winnicott (1960) indicated that individuals do not exist apart from the totality of their interpersonal relationships.
Through intersubjective moments of meeting there is a joint attention and sharing of subjective perspectives and meaning. This joint attention provides a greater understanding of the situation, creating a co-construction of new meaning. Joint attention is the precursor for co-regulation of affect, or affective attunement which permeates the intersubjective experience (Hughes, 2007).

In their work on the interactional nature of relationships, Atwood and Stolorow discussed the concept of the “myth of the isolated mind” (1992). The authors state that intersubjectivity enables individual to become affectively and cognitively present with each other, echoing Winnicott’s statement. Stern describes this as a situation whereby “two people see and feel roughly the same mental landscape” (2004, p. 75). When a parent/caregiver sees and feels a child’s mental landscape, the child feels “felt” which supports a secure attachment.

Related to this is Stern’s concept of “changing with the other” or a mutual regulation process across time (2004). Through co-constructive, co-regulative moments of meeting, each member of the dyad is changed, which in turn changes the actual relationship. Changing with the other is an integral part of the intersubjectivity of psychotherapy and parent/child relationships.

**Bidirectional agentic influence.** Bandura (2001) refers to the capacity of exercising control over one's life by initiating purposeful behaviour to influence another person as agency. Agency facilitates the individual’s ability to interpret and construct meaning of intersubjective experiences. Historically, research focused on a unidirectional approach to parent (caregiver)/child relationships. The parent was the active agent in the relationship, imparting knowledge, values, and behaviours to children (Kuczynski, Harach, & Bernardini, 1999). There is a growing body of research exploring children’s agency within a bidirectional framework (De Mol & Buysse, 2008; Knapp, 1999; Kuczynski, 2003). Bidirectionality involves children and parents in a relationship where meaning about self and other is co-constructed with agentic
influence and is mitigated with social-cultural factors (Kuczynski, 2003; Kuczynski & Lollis, 2004). The parent/caregiver and child influence, and are influenced by, each other.

**Intersubjectivity and family processes.** Intersubjectivity has been woven theoretically into family processes. Stern (2000) stated that the intersubjective space can be shared by parents or caregivers (adults or older siblings) and a child or children. He supplemented this notion by stating that the intersubjective experience of a family is continually evolving as the family grows and changes across its life cycle through diverse experiences. Finally, Stern stated that a “shared intersubjective history is part of the glue that defines the family’s identity” (p. 98). Hughes (2007) added that intersubjectivity can be initiated and experienced “across three people’s minds and hearts, just as they are across two, or even four or five, or a symphony” (p. 45).

**Situating Attachment and Intersubjectivity in Advanced Cancer and Anticipatory Loss**

Lyons-Ruth (2003) theorized that “without intersubjectivity, attachment security would be limited in its organization and meaning. Without secure attachment figures, intersubjective experiences would be limited in their developmental range and power to influence what we know and who we become” (p. 14). The uncertainty of advanced cancer and anticipated loss are emotionally charged experiences for children and parents, encompassing aspects of both attachment and intersubjectivity. As a child’s worst fears are being realized, he/she must cope not only with the death of a parent, but also with the death of a way of life. The anticipated loss for a child is profound as their sense of emotional security is threatened. Children struggle with overwhelming emotions in the absence of the emotional holding and containing they may have been able to access in other times of distress.

Further to this, if the well parent or caregiver is unavailable due to his or her own emotional turmoil, the child may portray a “false self” being strong for others (Forrest et al.,
Winnicott (1965) indicated that the concept of the false self is primarily defensive, protecting the true self from emotional harm. He contended that a parent’s ability to recognize, and consistently respond to, a child’s spontaneous expression of needs resulted in the emergence of a child’s true self. In the absence of this ability by a parent, the child portrays a false self as a form of insulation against further emotional distress. In the anticipatory loss of a parent, it can be hypothesized that a child’s need to portray a false self could serve a double purpose; to protect the child from overwhelming thoughts and feelings in the absence of an emotional anchor, and the child’s need to protect the parent(s).

The intersubjective space when a parent is dying is shared by the child or children, the dying parent and the well parent or caregiver. This space is filled with conscious and nonconscious emotional currents associated with uncertainty of illness and dying (fear, worry, sadness, anger, love). Shared emotional experience can facilitate affective attunement. The well parent or caregiver can step into the child’s emotional shoes as he or she knows what the impending loss of his or her partner means on an adult level. This supports the child’s sense of felt security. In the intersubjective space, the parent can reflect on the meaning of the crisis for the child, facilitating a co-construction of meaning regarding the impending death.

The “myth of the isolated mind” holds relevance to children coping with the impending loss of a parent. Often parents keep the child/ren in isolation as a form of protection from the angst and pain of the dying time (Hilton & Elfert, 1996; Kennedy & Lloyd-Williams, 2009b; Walsh, Manuel, & Avis, 2005). Children intuitively sense the emotional changes in their parents, however, knowing something significant must be happening. Lack of communication adds to the confusion felt by the child. It could be posited that children may struggle as they ‘read’ the emotions and unsaid words of their parent(s), dispelling the “myth of the isolated mind”.
Developing joint attention and attunement in the intersubjective space will help the child to find ways of coping, rather than struggling emotionally in isolation.

From the moment of diagnosis, cancer changes the ill parent, the well parent, and the children, “changing with the other” (Stern, 2004). Issues such as treatment and side effects, caregiver burden, and sharing in the dying time can impact the emotional tenure of the family. The actual death of a parent changes the parent/child relationship forever; something the child will never again experience in the tangible sense. The loss may result in changes for a child with regard to social location and positionality. Such loss has the potential to create a sense of difference or otherness for the child with respect to peers who have not experienced the death of a parent. The well parent is also changed through the dying time, dealing with his/her own anticipated loss and life without his/her partner. Additionally, the dying parent is changed, not only physically, but also emotionally. The shared reality of dying and death encompasses mutual changing with the other.

Situating advanced cancer and anticipated loss in the relational framework of attachment and intersubjectivity has illuminated areas of potential struggle for children. The importance of assisting parent(s)/caregivers in understanding the meaning for the child of the loss of the attachment relationship with the dying parent is evident. Bowlby (1973, as cited in Zelenko and Benham, 2002, p. 202) suggested the quality of caregiving from a new caregiver on separation from an attachment figure is one of the most important factors in a child’s adjustment to loss.

The following section provides an examination of the neurobiology of these relational processes.

The Neurobiological Underpinnings of Attachment and Intersubjectivity

“We come into the world wired to make connections with one another” (Siegel, 2007, p. 11). Seminal research has focused on the neurobiology of interpersonal relationships, and more
specifically how humans use close relationships to gain and maintain “felt” security (Badendoch, 2008; Balbernie, 2007; Hughes, 2007; Johnson & Whiffen, 2005; Schore & Schore, 2008; Siegel, 1999, 2004, 2007; Stern, 2004). This discussion of the neurobiology of attachment and intersubjectivity, and its relevance to advanced cancer and anticipatory loss will further the understanding of the lived experience of children and parents. Although neuroscience was not part of the research for this doctoral study, it holds relevance as it underpins various aspects of the theoretical framework. Additionally, neuroscience is an important aspect of social work education and practice.

**Attachment – a regulatory theory.** “There are no single brains” (Cozolino, 2006, p. 6). Humans are hard-wired to live in relationships across the life span. Applegate and Shapiro (2005) concluded that the bidirectionality of interpersonal relationships is associated with a right brain to right brain regulation of affect. Research has revealed that the regulation of emotion is a crucial function of attachment and relationships across the lifespan (Cozolino, 2010; Schore, 2003, 2011; Siegel, 1999, 2004; Tronick, 2007). Attachment is now seen as a regulatory theory.

Attachment shapes the early organization of neurobiological processes in the right brain involved with emotional safety and optimal development (Siegel, 1999; Sroufe, 2011). This is significant for parent/child relationships, particularly when children encounter situations evoking strong and scary emotions. In such situations, the parent or trusted adult acts as a crutch (right brain to right brain) for a child’s emotional development and regulation (Schore, 2005). As children grow and learn through experience, their ability to internalize their parent’s emotional crutch enables them to work through strong emotions and cope with challenging life situations.

**Bids for emotional connection – attachment communication.** Crucial to attachment is the implicit, nonconscious right brain to right brain affective communication between individuals
The orbital frontal cortex and limbic system (specifically the amygdala and hippocampus) of the right brain are essential to attachment communication. Schore (2003) theorized that bids of emotional connection and responses encompass attachment communication. Consistent attuned responses by a sensitive parent or caregiver are received by integral areas of the child’s right brain that are responsible for reading faces, voices and gestures. This creates “felt” security, disarming the attachment system (Sroufe, 2011). Johnson posited that a similar process of attachment communication exists in adult relationships in which partners develop an effective dependence grounded in felt security (2004, 2011). In times of emotional distress, an adult can turn to a partner knowing that he/she will be there. This has implications when facing the loss of a partner. Attachment focused communication has been extended to family relationships (Hughes, 2007, 2011). Whether initiated by an infant, child, or adult, bids of emotional connection represent one nonconscious mind communicating with another nonconscious mind (Schore, 2011).

**Neurobiology of intersubjective - mental state resonance.** Mental resonance represents the foundation for intersubjectivity. As two individual states are brought into alignment, mental state resonance occurs; a feeling that one is inside the mind of another (Siegel, 1999, 2004). Individuals influence, and are influenced by, each other, allowing internal states to resonate. A child’s brain self-regulates and self-organizes through the emotional attunement of the parent. This interpersonal integration, or visceral emotional template, is at the heart of intersubjectivity (Cozolino, 2006; Schore & Schore, 2008; Stern, 2004).

Affective attunement is associated with mental state resonance in interpersonal relationships. Attunement, according to Stern (2004), fills the intersubjective space with implicit communication of affective states between the right brains of parent/child or adult partners.
Hughes (2007) posited, “When two individuals are emotionally and cognitively engaged intersubjectively, each person’s affect is being co-regulated and they are co-creating meaning of the event experienced” (p. 14). An interesting aspect presented by Siegel (2004) is that mental state resonance can occur between two people after they are no longer in direct communication and are physically apart.

**Additional neurobiological aspects of interpersonal relationships.** Additional aspects related to the neurobiology of attachment and intersubjectivity warrant being included in this section as they further illuminate aspects of parent/child relationships and the uncertainties of advanced cancer and anticipated loss.

**Polyvagal theory and social engagement.** The autonomic nervous system, specifically the role of the vagus nerve (tenth cranial nerve) has been the focus of research by Porges (2001, 2003, 2007, 2015). Porges outlined the polyvagal theory, a neurobiological based social engagement system developed to facilitate safety, social interaction and healthy development. “The polyvagal theory links the evolution of the autonomic nervous system to affective experience, emotional expression, facial gestures, vocal communication and contingent social behavior” (Porges, 2007, p. 116). It is important to include this theory and the social engagement system in the discussion as it has direct application to the neurobiology of interpersonal relationships. Porges argued, “Missing from traditional attachment theories is an articulation of the mechanisms mediating engagement between the individuals bonding or forming attachments” (2003, p 33).

Porges’ research revealed that the parasympathetic nervous system contains two branches of the vagus nerve or vagal circuits. These circuits, in conjunction with the sympathetic nervous
system, respond to interpersonal or physical environments in the fight-flight-freeze or rest patterns as indicated previously. With regard to this circuitry, Dana (2015) noted the following:

From the brain stem at the base of our head, the vagus travels in two directions; down through our lungs, heart, diaphragm, and stomach and upwards connecting with nerves in our neck, throat, eyes, and ears. The vagus is divided into two parts; the ventral vagal pathway and the dorsal vagal pathway. The ventral vagal pathway supports feeling safe and social. When we feel comfortable and connected our ventral vagal system is online and in charge. On the other hand, the dorsal vagal pathway responds to signals of extreme danger. It takes us out of connection, out of awareness and into a protective state of collapse. When we feel frozen, numb, or “not here” the dorsal vagal system has taken control. (p. 1-2)

Porges posited the process of neuroception is integral to the polyvagal theory. Neuroception enables the conscious or nonconscious evaluation of a situation for cues of safety, danger, and life-threat. An ensuing physiological response with social engagement results in a fight-flight-freeze or rest response (2001, 2007). Porges further contended that “the social engagement system uses cues from verbal and non-verbal aspects of face-to-face interactions to calm physiological states and shift fight/flight/freeze behaviors to trusting relationships” (2015, p. 4). Figure 3 on the following page illustrates the social engagement system.
Siegel (2012) indicated, “The social engagement system, by dampening defense systems and the “stress” response, is associated with a receptive state that enables the individual to efficiently and enjoyably interact with others” (p. A1-61). This can be seen in secure attachment relationships. Porges posited that social engagement strategies are integral to the processes of attachment and the formation of social bonds (2003, p. 42). In discussing the polyvagal theory and attachment Lindaman (2016) stated,

Our use of safety cues from the face and voice of another is not a learned behavior but an evolutionary adaptation of mammals that begins in the infant-caregiver relationship. This neurophysiological experience of felt safety is the foundation of the attachment process.

We seek cues in the faces and voices of others and can be calmed by those cues. In this calm/optimal state we can be socially engaged, play, rest and be physically close to others. In this state we can access our higher level brain structures and our highest level of functioning. (para. 18)
Mirror neurons – root of empathy. The root of empathy is linked to areas in the brain called mirror neurons and resonance circuits (Applegate & Shapiro, 2005; Cozolino, 2006; Siegel, 2007, 2010). Specific mirror neurons located in the posterior parietal lobe, the superior temporal sulcus and the insula enable an individual to comprehend the emotional states of others. “We feel another’s feelings by actually feeling our own; knowing me, knowing you” (Siegel, 2010, p. 62). Resonance circuits encompass the neurobiological pathway enabling this empathic understanding. Acting quickly and outside conscious awareness, resonance circuits originate from mirror neurons connecting subcortical regions to the middle pre-frontal cortex (Schore, 2003; Schore & Schore, 2008; Siegel, 2007, 2010).

Initially, an individual takes in through the senses the conscious and nonconscious communication and actions of another individual. The mirror neurons then perceive these emotional bids for connection as intentional, and a person’s limbic system and bodily states are altered to match what is seen in the partner (Siegel, 2007). The term limbic resonance describes this attunement of emotional states; “a symphony of mutual exchange and internal adaptation whereby two mammals become attuned to each other’s inner states” (Lewis, Amini, & Lannon, 2000, p. 63). This mind to mind neural integration by mirror neurons facilitates intersubjectivity and secure attachment relationships (parent/child or adult partner). Bräten (2006) captured this noting, “When we engage in mirroring, we involve ourselves in the other person’s actions as if we are seated at the centre of the other person’s body” (as cited in Hart, 2011, p. 46).

Mindsight. Siegel’s concept of mindsight can be equated to our seventh sense and is the heart of empathy and nurturing relationships (2004, 2006, 2010). Mindsight enables an individual to perceive his/her own mind and the mind of others. Similar to an internal working model, mindsight facilitates the creation of “me maps” of past, present and future experiences in
the pre-frontal cortex. Siegel stated that empathy develops through mindsight as an individual creates “you maps”, knowing the person from the inside out. Mirror neurons and neurobiological pathways make “you maps” possible. Finally Siegel contended that “we maps” can be seen as a right brain to right brain process of attachment and intersubjective relationships, in essence a form of co-empathy. Mindsight holds significant relevance to attachment and intersubjectivity, particularly the neurobiology of knowing self and other. Through attachment and intersubjective relationships, parents (and significant adults) enable children to develop mindsight maps.

**Situation the Neurobiological Underpinnings of Attachment and Intersubjectivity in Advanced Cancer and Anticipatory Loss**

Coping with the emotional and cognitive meaning making during this time of uncertainty and distress involves a child’s full brain. The connections between the brains of the child and parents are of importance. Holding and containing (emotional provisioning) by the parent(s) has significance in calming a child. Mental state resonance between parent(s) and child supports a child’s attempts to deal with scary thoughts and feelings. Attuned attachment responses to a child’s bids of emotional connection instill felt security. A child’s distress may heighten if these bids are met with what could be termed mental state dissonance. The parent(s) may be emotionally unavailable even though they are coping with the same experience. In essence, the right brain to right brain need for emotional regulation may not be accessible to a child.

Anticipating the loss of a parent and emotional security can set up a neurobiological double bind for a child. With increased distress, neurobiological structures enact a child’s bids of emotional connection to gain felt security. The natural antidote for this distress would be the safe haven, secure base of an attachment figure. If this person is dying, or if he/she is emotionally unavailable due to caregiving, distress is heightened. Hart (2011) indicated a stressed attachment system results in a decrease in the release of attachment hormone, thereby maintaining the
activation of the amygdala. This could result in continuing the neurobiological response to distress, reinforcing the child’s loss of the parent and emotional security.

With regard to the polyvagal theory, social engagement, mirror neurons and empathy, it could be posited that a child may sense the parents’ emotional reactions as a form of limbic resonance; able to ‘feel’ their distress. The parents’ need to protect a child may result in telling the child that things are fine. This can create mixed messages for the child as the verbal message is not consistent with the non-verbal distress sensed by the child. Discussing the emotions felt by parents and child through attachment focused communication (verbal and non-verbal) in the intersubjective space will help the child.

Finally, mindsight holds relevance to the emotional and neural connection between parents and children coping with this uncertainty. These connections shape the child’s implicit knowing of the situation. It could be argued that as the child realizes and copes with the emotional and physical loss of a parent, his/her ‘me’, ‘you’ and ‘we’ maps are re-defined. If the surviving parent is aware of the meaning of the emotional loss for the child, this parent can strengthen his/her role as an emotional anchor and the child’s working model or mindsight can re-adjust. This can facilitate a co-construction of meaning of what may be overwhelming and scary.

**Theoretical Model**

The theoretical framework outlined in this chapter supported an in-depth understanding of the experiences of children and parents coping with advanced cancer and anticipatory loss. Using this theoretical framework as a base, a theoretical model has been developed to capture the construction of meaning, reflective of diverse understandings. Siegel indicated that what is sharable is bearable (2007, 2010), which aptly summarizes the emphasis of this model.

Supporting the child’s agentic influence in giving voice to his/her thoughts and feelings, and the
parents’ understanding of their child’s needs, will enable distressing circumstances to be sharable and, therefore, bearable.

The pivotal focus of this model is represented by the intersubjective space of illness and impending loss shared by the child, well parent or caregiver, and the dying parent. This space is interwoven with the neurobiological aspects underpinning interpersonal relationships. The emotional bond of attachment security creates a safe haven, secure base for the child who will feel “felt”, or emotionally held within the intersubjective space. The child’s agentic influence and authentic voice can be promoted within this space. Development across middle childhood and adolescence provides a child with a keen subjective awareness of what the impending loss means. Moreover, the concept of the child as a determiner, rather than as determined, will be reinforced. Affective attunement and emotional responsiveness, in addition to scaffolding provided by the adults (or more knowledgeable others, MKO), will help a child to know what he/she is thinking and feeling is valid. Furthermore, through bidirectional mental state resonance the parent(s) and child will adapt and change with each other while living with the impending loss (of a parent and life partner). Hughes captured this with his comment, “Through intersubjective experiences, the subjective experiences of one contribute to the development of the subjective experiences of the others, and vice versa” (2011, p. 16).

Unique to the theoretical and empirical literature, the model presents an innovative and insightful way of developing a comprehensive understanding of this compelling issue.
Living with Uncertainty: The Experiences of Parents and Children When a Parent is Living with, and Dying from, Advanced Cancer

Factors Affecting Outcomes of Child and Parent
- Communication
- Caregiver Burden, Emotional Distress, Uncertainty
- Role Reversal/"False Self"

Construction of meaning
- Social Constructivism
- Sociocultural Theory

Developmental Aspects
- Middle Childhood
- Adolescence
- Diversity

Attachment Relationship

The Intersubjective Space of Illness and Anticipatory Loss

Well Parent or Caregiver

Meaning of the Experiences of Children and Parents

Dying Parent

Neurobiological Underpinnings

The Intersubjective Space of Illness and Anticipatory Loss

Attachment Relationship

Parent's Advanced Cancer and Anticipated Death

Social Work Education and Practice

The Intersubjective Space of Illness and Anticipatory Loss

Attachment Relationship
Summary - Weaving the Theoretical Framework Together

Loss in childhood can have a deep impact on the growing mind as a seemingly irreparable void is experienced by a child (Bowlby, 1982; Sroufe, 2011). The physical and emotional complexities of advanced cancer and anticipatory loss are faced by the dying parent, the surviving parent and child, on an individual and a relational level. As De Mol and Buysse commented, “parents and children cannot be understood as discrete individuals” (2008, p. 165). Children have a need to feel “felt” (“felt” security). They look to trusted adults (more knowledgeable others) to guide them in times of uncertainty. Scaffolding, affective attunement, joint attention, bidirectional agentic influence, in conjunction with neurobiological processes are of importance. Moments of meeting within the intersubjective space can facilitate the co-construction of meaning (social constructivism, and sociocultural theory) and co-regulation of affect (relational theories). This can, in turn, support positive outcomes for children and parents.

Finally, Vance noted that secure relationships serve as the primary antidote for fearful or painful experiences (1997, as cited in Rich, 2007, p. 4). He added that childhood distress often abates as a result of specific relationships through secure attachment or close mentor relationships. This aptly describes the theoretical framework and model outlined in this chapter, pivotal to this doctoral research focusing on this time of great uncertainty.
Chapter Four  
Research Design and Methodology

This chapter will outline the steps in the research process for this doctoral study, including aspects of the research design, the collection and analysis of the data, and strategies for rigor. An outline of the ethics review process will also be provided.

Qualitative Methodologies

This qualitative research study was informed by interpretive methodologies. Supportive of this research, such a methodology involves a nonlinear research path, interpretation of subjective meaning, social and cultural context, and the privilege of lay knowledge (Denzin & Lincoln, 2000; Fossey, Harvey, McDermott & Davidson, 2002; Neuman & Robson, 2009; Yardley, 2000). Moreover, such methodologies “offer a complimentary set of investigative approaches which can bring fresh insights into health and illness” (Yardley, 2000, p. 216). Finally, in relation to the dearth of empirical literature discussed in Chapter Two, a qualitative inquiry is appropriate when there is little known about a particular research area or when a research topic is highly complex (Elliott & Timulak, 2005).

Specific Qualitative Methodology – Phenomenology

The particular qualitative methodology which informed this research design was phenomenology, which is both a philosophical movement and a research methodology. Part of the constructivist interpretivist paradigm (Cohen, Kahn, & Steeves, 2000), this methodology is congruent with the theoretical framework of this doctoral study (as outlined in Chapter Three). Aligned with the focus of the current research, phenomenology explores the essence of individual meaning and perceptions of lived experiences as critical factors for understanding a phenomenon (Creswell, 2002; Moustakas, 1994; Smith, Flowers, & Larkin, 2009; van Manen, 2014). Heidegger (1927, 1996) aptly indicated that “phenomenology puts in light or manifests
something that can become visible in itself” (p. 51). Moreover, Halldorsdottir noted, “Phenomenology is not a single, unified body of thought and one may find multiple interpretations and modifications of phenomenological philosophy and its use as a research method for studying the lived experience of human beings” (2000, p. 48). Halldorsdottir’s comments provide validation for the use of phenomenological research methods, especially in light of the potential for divergent interpretations of the experiences of cancer within family members, and amongst different families.

As lived experience is the focal point of phenomenological research, it is important to provide context for this. van Manen (2014) stated, “Lived experience names the ordinary and the extraordinary, the quotidian and the exotic, the routine and the surprising the dull and the ecstatic moments and aspects of experiences as we live through them in our human existence” (p. 39). What represents an individual’s truth and reality is shaped by lived experience. Further to this, Pascal (2010) contended, “Through accessing lived experience researchers may gain understanding of the meanings and perceptions of another person’s world” (p. 6). This has relevance to the experience of the research participants, particularly children trying to make sense of a parent’s advanced cancer.

Three major schools of phenomenology have arisen, each focusing on the essence of lived experience: (1) eidetic or descriptive phenomenology rooted in the work of Husserl; (2) hermeneutic or interpretive hermeneutic rooted in the work of Heidegger and Gadamer; (3) the Dutch school of phenomenology rooted in the work of van Manen (Dowling, 2007).

**Hermeneutic interpretive phenomenology.** Hermeneutic interpretive phenomenology was the specific approach to phenomenology used in this research. Cole stated, “It is this move to interpretive practice that marks a key distinction between purely phenomenological research
seeking rich lifeworld descriptions of the lifeworld, and hermeneutic phenomenological research that seeks to understand these worlds from participants’ perspectives” (2010, p. 1). Informed by Heidegger, this approach enabled detailed investigation of the phenomenon from the participants’ unique frame of reference, and in particular how they make sense of their experience (Crist & Tanner, 2003; Smith, 2003).

The work of Heidegger. Central to Heidegger’s ontological position (1927, 1996) was his conception of existence or “Dasein” (being-in-the-world). Heidegger theorized that because many elements that shape Dasein are hidden and require interpretation to be understood, it is important to uncover the hidden phenomena and their meanings (Wilcke, 2002). Smith, Flowers, and Larkin (2009) elaborated on this noting, “Heidegger questioned the possibility of any knowledge outside of an interpretative stance whilst grounding this stance in the lived world – the world of things, people relationships and language” (p. 16). As a result, interpretation is seen as critical to the process of understanding (Laverty, 2003).

Heidegger proposed the notion of “fore-conceptions” or prior experiences, assumptions and preconceptions. “The reader, analyst, or listener brings their fore-conception to the encounter, and cannot help but look at any new stimulus in the light of their own prior experiences” (Smith et al., 2009, p. 24). Heidegger did not believe it possible to bracket one’s fore-conceptions as they are part of being-in-the-world, and the research process.

Heidegger further incorporated the concept of intersubjectivity with reference to individuals’ shared, overlapping, relatedness-to-the-world (Smith et al., 2009). Further to this, Heidegger proposed that intersubjectivity involved “co-created and mutual research relationships between the researcher and the researched with both representing a significant source of knowledge” (Pascal, 2010, p. 8). Heidegger’s inclusion of intersubjectivity links directly the
intersubjective space shared with parents/caregivers and children when a parent is living with, and dying from, advanced cancer as outlined in Chapter Three of this dissertation.

Finally, Heidegger considered research as a circular process inclusive of culture and history, incorporating the Hermeneutic Circle through which the understanding of texts is distilled to a place of sensible meaning (Laverty, 2003; Smith, 2003). This aspect of Heidegger’s approach is significant as aspects such as culture and history can’t be separated from individuals’ stories, making them unique. The hermeneutic circle focuses on the relationship and movement between the parts (data) and whole (evolving understanding of the phenomenon). Ajjawi and Higgs (2007) proposed, “Each gives meaning to the other such that understanding is circular and iterative. The circle is continued with the researcher going back through the texts several times to gain a true appreciation of the story” (p. 623). For this doctoral candidate, the image of a circle resembles inclusivity and joining of the researcher and the participant to develop an understanding and interpretation true to the meaning of lived experience. Figure 5 provides a depiction of the hermeneutic circle (Bontekoe, 1996, as cited in Ajjawi & Higgs, 2007, p. 623).

**Figure 5. Hermeneutic Circle**
The work of Gadamer. The use of hermeneutic interpretive phenomenology (HIP) will be further informed by the work of Gadamer, who contended, “The miracle of understanding is not a mysterious communion of souls but sharing in a common meaning” (1989, p. 292). Human understanding, according to Gadamer, is inter-subjective and emerges between partners in genuine or authentic conversation (Jones, 2004; Newberry, 2012). Gadamer felt strongly that the researcher has a bond with the subject matter, seeing language and understanding as inseparable (Laverty, 2003). He used the term ‘fusion of horizons’ to describe this interconnectedness and shared understanding to achieve a deeper, but not definitive, insight of a phenomenon. Fleming, Gaidys and Robb (2003) noted, “Gadamer believed that understanding and interpretation are bound together and interpretation is always an evolving process, thus a definitive interpretation is likely never possible” (p. 117). Gadamer questioned whether an individual can come to a definitive interpretation of another human’s lived experience, therefore removing the interpretation from definitive.

Gadamer also contended, “The researcher cannot be detached from his/her own presuppositions and that the researcher should not pretend otherwise” (Hammersley, 2007, p. 7). Gadamer (1976) proposed that understanding is not possible without preunderstandings of the phenomenon of interest, and these preunderstandings are visited again during the process of gaining understanding through a process of reflection. “Understanding, therefore, always implies a preunderstanding” (as cited in Fleming et al., 2003, p. 116). Elaborating on Gadamer’s concept, Laverty (2003) noted, “Preunderstanding is not something a person can step outside of or put aside, as it is understood as already being with us in the world” (p. 8). Moreover, van Manen (1990) argued that when researchers try to forget or ignore their own experiences, they might find that “the presupposition persistently creeps back into” their reflections (p. 47).
It is for this reason that Fleming et al., argued, “Researchers underpinning their work with the philosophy of Gadamer are required to identify their preunderstandings or prejudices of the topic. Reflecting upon these will enable them to move beyond their preunderstandings to understand the phenomenon and so transcend their horizon” (2003, p. 117).

**Researcher’s preunderstanding.** As a person who continually engages in personal and professional introspection, this doctoral candidate’s preunderstanding is reflective of her ‘reality’ based on her background, social location and positionality in relation to this research focus. Having worked with children and families for more than 35 years, this rich understanding has enabled this candidate to view children as a diverse social group and active agents with keen desires to make sense of their worlds, especially what is uncertain or scary. She firmly believes that children are experts on their own lives, and actively construct their reality through shared meaning making, initially with parents (or caregivers), and then with peers and significant adults.

Capturing the lived experiences of children and parents/caregivers and developing an in-depth understanding is of importance to this candidate, due primarily to her own lived experience personally, professionally and academically. She has encountered cancer directly through individuals close to her and through individuals she has supported. As a young adult, this candidate lost her father to advanced metastatic pancreatic cancer over the course of a few weeks, which enabled her to know the profound sadness felt in one’s heart and spirit. She has also faced the loss of other family members, and close friends who are considered ‘family’.

Professionally, this candidate’s specific work in oncology and palliative care began while completing her first year MSW practicum. Several individuals on her case-load were diagnosed with advanced cancer, had recurrences, moved to end of life and died. She supported the individuals who were dying in making meaning of their life circumstances, and in grieving the
loss of their own life, and relationships dear to them. She supported family members in the reality of the anticipated and actual loss of their loved one. Upon graduation, this candidate became a child and family therapist for a cancer support agency, in addition to her own private practice and role as a clinical social worker for a regional children’s mental health agency. For more than 15 years, she provided individual, family and group counselling for patients and their families from diagnosis, to crisis, to palliative care, and through dying and death. During that time, her personal and professional selves were clearly shaped by the diversity of each situation – culture, age, gender, health status, ability, and financial, in addition to others aspects of humanness. Being deliberately inclusive and learning one from the other was important to this candidate. It was through these situations that she learned to be open to the authenticity and diversity of the dying time, being present, and taking the lead from individuals and families.

In penning this preunderstanding of her lived experience personally and professionally, this candidate is aware of the fluid nature of being human, and knows there will be at least one occasion during the research when she will wonder about what is resonating for her. van Manen referred to this as “hermeneutic alertness” (as cited in Ajjawi & Higgs, 2007, p. 622). Drawing on the writing of Fleming et al., this reflexive piece will hopefully enable her to move beyond her preunderstanding to understanding the phenomenon and transcend her horizon (2003).

Finally, although this candidate has a wealth of personal and professional lived experience, in conducting and analyzing each research interview, she hopes that she will able to be continually open to sitting with the individual participants, growing as a researcher, social worker and person. Newberry aptly describes this by noting,

Entering with clients this way, often acting as a witness to both the darkest and most life-giving experiences of human life, changes the social worker in some very fundamental
way. The committed social worker will enter again, and again, and again into these places, coming out each time as someone at least slightly changed. (2012, p 15)

**Social work and hermeneutic interpretive phenomenology.** In addition to the congruence of hermeneutic interpretive phenomenology with the focus of this research, HIP is congruent with a key facet of social worker practice, that of understanding an individual’s subjective experience and the meaning he/she makes of that experience. As Newberry (2012) contended, interpretive inquiry is highly consistent with social work due to its inclusion of concepts of (situated) agency, closeness to subjects (with subjects understood as human actors), and a critical inter-subjectivity that seeks to disrupt oppressive social discourses through a hermeneutic understanding that connects. (p. 1)

Further to this, the work of Heidegger and Gadamer supports an interpersonal or intersubjective approach which is congruent with the underpinnings of social work (Newberry, 2012, p. 15).

**Concluding thoughts regarding hermeneutic interpretive phenomenology.** Hermeneutic interpretive phenomenology informed by the work of Heidegger and Gadamer was viewed as an appropriate methodology for this doctoral study. As noted, this methodology is congruent with social work. It is also congruent with the research questions of this study aimed at developing an understanding of the complexities of the experiences of children and parents coping with incurable illness such as advanced cancer.

**Research Methods and Process**

Charmaz (2006, p. 14) noted the following with regard to research methods which holds relevance to this doctoral research:

Methods extend and magnify our view of studied life and, thus, broaden and deepen what we learn of it and know about it. Through our methods, we first aim to see this world as
our research participants do – from the inside. Although we cannot claim to replicate their views, we can try to enter their settings and situations to the extent possible seeing research participants’ lives from the inside often gives a researcher otherwise unobtainable views.

This section will outline the research methods and process for conducting this study, as indicated in a detailed Study Protocol approved by the University Health Network Research Ethics Board, Princess Margaret Cancer Centre (Appendix A), and the University of Toronto Research Ethics Board (Appendix B). The discussion will include the sample description, recruitment strategies, methods of data collection and analysis, strategies for rigor, and ethical considerations.

**Research Questions**

As stated in Chapter One, the research questions which guided this interpretive inquiry are:

5) How do children and their parents (ill parents and well parents or caregivers) construct meaning of the parent’s cancer?

6) How do children and their ill parents, well parents or caregivers talk about coping with the parent’s cancer (specifically the threat to children’s emotional security and perceived changes to the attachment relationships, the child’s sense of self and social location)?

7) What is the experience of children and their ill parents, well parents or caregivers with formal and informal supports within and outside the cancer centre?
   a) What do children and parents find helpful and unhelpful in coping with the parent’s cancer?

8) How can the experiences of both children and parents or caregivers better inform social work education and practice, in turn supporting the creation of developmentally appropriate short- and long-term support strategies for children and families coping with a parent’s advanced terminal cancer?

Additionally, the purpose of the research questions was to gain an understanding of (1) the parents’ perspectives; (2) the parents’ perspectives of their children’s experiences; and (3) the children’s perspectives
The Participants, Recruitment Strategies and Sample Description

This study was conducted at the Princess Margaret Cancer Centre, University Health Network, Toronto, Ontario. Patients with terminal cancer with an expected survival of less than 24 months and their families formed the basis of the sample (specifically ill parents, well parents or caregivers, and children, six to eighteen years of age). The expected survival was based on three research studies conducted by Dr. Rodin’s research team in the Department of Supportive Care, which formed the basis of recruitment for this doctoral study. Participants were sought through the use of nonprobability purposive sampling, sampling with a purpose to identify participants who are representative of relevant dimensions of the target population (Creswell, 2007; Kreuger & Neuman, 2006).

Inclusion and exclusion criteria and withdrawal of subjects. The following outlines the inclusion, exclusion and withdrawal criteria for potential participants as outlined in the approved Study Protocol (p. 16-17):

Subject inclusion criteria:

a) Patients diagnosed with advanced or life limiting cancer (broadly corresponding to an expected survival of less than 6 to 24 months);

b) Well parents or caregivers;

c) If one parent consents to participate in the study but the other parent or caregiver does not provide consent or is too ill to participate, the family will be included in the study;

d) Children six to eighteen years of age;

i. As this proposed research captures children’s meaning making of the cancer of a parent, it is necessary that the children be aware of their parent’s cancer in order to be included in the study.

e) All participants must be sufficiently fluent in English (both receptively and expressively) to answer the interview questions. In addition parents must have sufficient literacy in English to understand and complete the Information Forms, and the Informed Consent and Informed Assent Forms.

Subject exclusion criteria:

a) Patients and well parents or caregivers and/or children that have limited skills in English (both receptively and expressively) representing barriers to providing informed consent/assent and/or understanding interview questions;

b) Cognitive impairment in the patient, well parent or caregiver and/or child
c) Children who do not provide their assent to participate in the study despite their parents providing consent.

d) In a two parent household, or separated or divorced households where parents have shared custody/decision making, when one parent agrees to provide consent for a child (children) to participate but the other parent does not agree to provide consent.

Withdrawal of Subjects - Participants may be withdrawn from the study if:

a) They choose to withdraw
   i. If parents, caregivers or children decide to leave the study, the information provided and that was collected before the participant(s) withdraws from the study will be used in the study. No new information will be collected without the respective participant’s permission. Additionally a participant’s decision to withdraw from the study will in no way affect the treatment of the parent with cancer at the Princess Margaret Cancer Centre, University Health Network

b) Cognitive impairment is detected
   i. Physical deterioration in health leads to inability to complete interviews

c) Death

**Research involving children.** The “paradox of the ‘missing child’” as discussed by Darbyshire, MacDougall, and Schiller (2005, p. 419) holds direct relevance to the research focus of this doctoral study. The authors contended, “The predominant approach to researching children’s experiences is grounded in ‘research on’ rather than ‘research with’ or ‘research for’ children, ignoring the views of children as active agents and ‘key informants’ in matters pertaining to their health and wellbeing (p. 419). As noted in Chapter Two of this dissertation, despite being deeply affected by cancer in a parent, there is a significant dearth in the literature incorporating the voices of children and adolescents as key informants. The result of this absence has led to a murky understanding of children’s experience coping with a parent living with, and dying from, advanced cancer. It is for this reason that the inclusion of the voices of children in this doctoral research was of importance; to provide first-hand accounts of their own lived experience. The position of including children in this research is supported by the following statement from the Ethical Research Involving Children Project (ERIC), “Research involving children is vital for understanding children’s lives. It ensures their experiences and perspectives
closely inform the study, providing accurate and culturally specific information, which consequently enhances the value and validity of the findings.” (Graham et al., 2013, p. 13).

Researchers have discussed the recent shift to include children in research, gaining information about children directly from children themselves (Christ, 2000; Darbyshire et al., 2005; Gill, Stewart, Treasure, & Chadwick, 2008; Greig, Taylor, & MacKay, 2007; Mishna, Antle, & Regehr, 2004). Kirk (2007) noted the “growing body of evidence that demonstrates that children can be competent participants in the research process as long as researchers recognise the ways in which children communicate and facilitate their participation” (p. 1251).

The shift to include children as active participants stems from the growing recognition of the rights of children. The United Nations’ Convention on the Rights of the Child (2009) recommended, “Respect for the child’s right to express his or her views and to participate in promoting the healthy development and well-being of children. This applies to individual health-care decisions, as well as to children’s involvement in the development of health policy and services”. (Article 98). This respect extends to the involvement in research (Article 104).

Moreover, Helseth and Slettebø (2004) noted:

The Declaration of Helsinki has traditionally limited research involving children by demanding special justification for including children in research regarding their health. In the latest revision, however, it is argued that, in future, special grounds should be demonstrated for excluding children from such research. It is acknowledged that children are unique and not just ‘small adults’, and that research results from an adult population are not necessarily valid for or transferable to a young population. The Declaration also states that, with regard to children’s life situation, their point of view should be regarded as being of equal importance to adults’ view. (p. 298)
It is further important to consider the appropriateness of qualitative methods in research with children. As discussed previously in this chapter, qualitative methods were chosen to enable a deeper understanding of the lived experiences of participants. This applies to the children participating in this study, validated by Mishna et al., (2004) who noted,

Qualitative research provides an opportunity to tap into the richness of children’s thoughts and feelings about themselves, their environments and the world in which we all live.

Through qualitative interviewing we are able to step outside the bounds of adult thinking and discover unexpected differences in the perceptions of adults and children. (p. 450)

Moreover, Greig et al. commented, “Children represent an excellent source of the kind of data that are at the heart of qualitative research – rich descriptions in words and pictures that capture children’s experiences and understandings” (2007, p. 138).

**Recruitment strategies.** Several strategies were utilized to identify potential participants for this study. Recruitment was initiated by Dr. Gary Rodin’s research team in the Department of Supportive Care associated with three research studies conducted at the Princess Margaret Cancer Centre: (1) UHN REB 12-5609-CE: A study of physical and psychological symptoms in patients with pancreatic and other gastrointestinal cancers (G. Rodin, PI; P. Fitzgerald, Co-I); (2) UHN REB 09-0855-C: A randomized controlled trial of a brief psychotherapy referred to as Managing Cancer and Living Meaningfully (CALM) for patients with metastatic cancer (G. Rodin, PI; S. Hales, Co-PI); and (3) UHN REB 12-0371-CE: A study of the experience of advanced cancer in young adults (G. Rodin, PI; M. Knox, Co-I). A link between these studies and this doctoral research was established for the purpose of identifying patients who met the inclusion criteria for the current study, specifically patients who had children six to eighteen years of age. An additional recruitment strategy involved consulting with health professionals
(oncologists, physicians, psychiatrists, psychologists, nurses, and social workers) at the Princess Margaret Cancer Centre working with patients diagnosed with advanced cancer who had children within the specified age range.

Once patients meeting the inclusion criteria were identified, patients’ consent was obtained to provide their respective names and contact information to this doctoral candidate. An Introductory Recruitment Letter for Patients (Appendix D) clearly outlining pertinent information about the study was sent to potential participants. This doctoral candidate then contacted each potential participant by phone to discuss the study and to ascertain interest, Telephone Recruitment Script (Appendix E). For those interested in participating, interviews were scheduled either at Princess Margaret Cancer Centre or in the patient’s home.

**Sample size.** Seven families, each meeting the inclusion criteria, comprised the sample for this study. The specific composition of the participant families involved seven ill parents (two fathers and five mothers), four well parents or caregivers (all fathers), and four children (two girls and two boys). A more detailed description of the participant families will be provided in Chapter Five – Research Findings.

**Validation of sample size.** Seven families encompassing fifteen participants represents an appropriate sample size as validated by the research. Qualitative research generally involves few participants due to the richness of the data, providing a deep understanding of the lived experiences (Charmaz, 2006; Kvale 1996). In addition, indicators related to the sample size for qualitative studies as discussed in the research, provide further validation of this sample size:

- For a phenomenological study, the process of collecting information involves primarily in-depth interviews with as many as ten individuals (Creswell, 2007, p. 131);
- Smith et al., (2009, p. 51) discussed a sample size for students conducting research as between three to six participants to provide sufficient data;
• Kuckelman-Cobb and Forbes (2002, p. M199) recommended six participant in order to discover the essence of an experience;

• Kvale discussed a sample size of between five to fifteen participants (1996);

• Seven factors affecting sample size were outlined by Ritchie et al., 2003, p. 84): (1) the heterogeneity of the population; (2) the number of selection criteria; (3) the extent to which ‘nesting’ of criteria is needed; (4) groups of special interest that require intensive study; (5) multiple samples within one study; (6) types of data collection methods use; and (7) the budget and resources available;

• Pietkiewicz and Smith (2014, p. 15) noted, there is no rule regarding how many participants should be included. It generally depends on: (1) the depth of analysis of a single case study; (2) the richness of the individual cases; (3) how the researcher wants to compare or contrast single cases; and (4) the pragmatic restrictions one is working under. The last category includes time constraints or access to participants. Researchers should concentrate more on the depth, rather than breadth, of the study.

**Saturation.** An additional aspect that is involved in sample size is saturation. According to Strauss and Corbin, the benchmark for judging saturation is “no additional data are being found whereby the researcher can develop properties of the categories (1998, p. 61). Mason (2010) noted, “While there are other factors that affect sample size in qualitative studies, researchers generally use saturation as a guiding principle during their data collection (para. 3). Guest, Bunce, and Johnson indicated the following guidelines in determining saturation: no new data, no new themes, no new coding, and ability to replicate the study (2006. p. 61). With reference to this doctoral research, the researcher noted saturation of the data following interviews with six families, consisting of eleven participants. However to enhance the qualitative data (Padgett, 2006; Smith et al., 2009), four members of a seventh family were interviewed. Although there were some unique aspects to the participants’ stories as discussed in Chapter Five, a recurrence of general themes in the stories of the children, well parents or caregivers, and ill parents was indicative of saturation.
Aims of study. An additional aspect having implications for sample size relates to the aims of a study as discussed by Charmaz (2006). This author contended that the aims of the study are “the ultimate driver of the project design, and therefore the sample size. A small study with ‘modest claims’ might achieve saturation quicker than a study that is aiming to describe a process that spans disciplines” (p. 114). These comments relate directly to this doctoral research.

In light of the indicators of sample size, saturation, and study aims, the sample size of seven families, fifteen participants, was appropriate for this phenomenological study with the goal of obtaining a varied, rich and deep understanding or essence of the participants’ experiences (Dibley, 2011; Kreuger & Neuman, 2005; Smith, & Osborn, 2007).

Data Collection

“How you collect data affects which phenomena you will see, how, where and when you will see them and what sense you will make of them” (Charmaz (2006, p. 15). Data collection for this doctoral study began with parents completing Demographic Information Forms for themselves and for the child (children) (Appendices J, K, and L). This basic demographic information (at the lowest level of identifiability possible) provided a general background for participants prior to the interviews.

The qualitative research interview. Described as “a conversation with a purpose”, the qualitative research interview represents an integral method of data collection in the phenomenological approach (Smith et al., 2009, p. 57). Kvale (1996) noted that this method “is literally an ‘inter view’, an interchange of views between two persons conversing about a theme of mutual interest,” whereby the researcher attempts to “understand the world from the subjects' point of view, to unfold meaning of people’s experiences” (p. 1-2). Extending this idea, Blumer used the term “intimate familiarity” to depict the use of a research interview to enable the researcher to develop a sense of closeness to the research focus (1969, as cited in Charmaz,
To develop this sense of familiarity with the focus of this doctoral research, qualitative interviews were utilized as the primary method of data collection. “What one seeks from a research interview in phenomenological research is as complete a description as possible of the experience that a participant has lived through” (Giorgi, 2009, p. 122). Such interviews enabled children and parents or caregivers to provide personal narratives of their experiences, leading to rich description fitting with interpretive research.

The specific format of this data collection involved digitally audio recorded, face-to-face semi-structured interviews with children, well parents or caregivers, and the ill parents. Semi-structured interviews incorporate “several key questions that help to define the areas to be explored, but also allows the interviewer or interviewee to diverge in order to pursue an idea or response in more detail. This interview format is used frequently in healthcare, as it provides participants with some guidance on what to talk about, which many find helpful” (Gill et al., 2008, p. 292). Chan, Brykczynski, Malone and Benner (2010) discussed the importance of “appreciating that interviews comprise access to disclosive spaces, as opposed to opportunities to interrogate participants,” which “helps position the researcher for understanding” (p. 18). The creation of disclosive spaces for the participants in this doctoral study, especially children, was important due to their vulnerability and the sensitive nature of the research focus. Finally in conducting interviews with children, Gollop (2000) proposed, “Researcher should think of interviews with children as conversation, listening to the children as opposed to interviewing them, and providing them with the opportunity to be heard” (p. 18).

Semi-structured qualitative interview guides (Appendices 12, 13, and 14) facilitated participants’ narratives (Cohen et al., 2000; Durrheim, 2006; Riessman, 2008). Each guide was composed of questions that fit with those used in qualitative inquiry to elicit detailed discussion.
as they are open-ended, evolving, non-judgmental, and non-directional (Charmaz, 2006; Creswell, 2007). A flexible approach to the interviews was important as it enabled certain topics to be explored more in depth, or to explore new areas of inquiry which were not anticipated (Patton, 2002). When other themes emerged during the interview process, the researcher remained flexible and open, providing space for participants to discuss their lived experience.

**Additional methods of data collection.** Additional methods of data collection were incorporated as a visual means through which participants could enhance the narrative information of their lived experience. Bagnoli stated, “The inclusion of non-linguistic dimensions in research, which rely on other expressive possibilities, may allow us to access and represent different levels of experience” (2009, p. 547). Further to Bagnoli’s comments, qualitative research with children and adults has used visual methods of data collection to provide an understanding of participants’ experiences that cannot easily be put into words (Adriansen, 2012; Christ, 2000; Deacon, 2000; Freeman & Mathison, 2008; Webb, 2005). Each of the methods used were developed by this doctoral candidate and therefore are non-standardized. Their purpose was to present a simple way to capture additional information that could be incorporated into the research interviews.

An Illness Time Line (Appendix P) was completed by parents prior to their respective interview to document the chronological sequence of the parent’s illness and any aspects involving the children (for example, when the children were informed of the initial diagnosis and the parent’s cancer status). A Worry Meter for Children (Appendix Q), a rating scale developed by this candidate in her clinical work with children, was completed by children to determine an understanding of the level of worry in relation to their parent’s illness. The parents living with cancer and the well parents or caregivers completed a Parent or Caregiver Distress Rating Scale
(Appendix R). This rating scale was adapted from the Worry Meter for Children by this candidate. It used the same rating scale, but allowed for more detail in the adults’ responses.

With respect to children’s ability to complete rating scales, such measures are used extensively in assessments of children. Examples are Spence Children's Anxiety Scale (SCAS) (1994); Weinberg Depression Scale for Children and Adolescents (WDSCA) (1998); Conduct Disorder Scale (CDS) (2002). The Worry Meter was considerably shorter than these rating scales for assessment purposes, and as such children were able to complete this relatively easily and accurately in accordance to their lived experience. The Illness Time Line and the Worry Meter/Distress Rating Scale enabled this doctoral candidate to gain a more detailed understanding of the participants’ experiences with advanced cancer. In addition, each measure provided a focus for discussion during interviews, as indicated in the interview guides.

Finally, a reflexive journal was kept to provide space for this researcher’s introspection and subjectivity. Ajjawi & Higgs contended it is important to “reflect on the meanings of situations, rather than accepting their pre-conceptions and interpretations at face value” (2007, p. 620).

Data collection process. This process followed a specific format as approved by the University Health Network Research Ethics Board and the University of Toronto Research Ethics Board. As previously indicated, the interviews took place in a confidential space in the Department of Supportive Care at the Princess Margaret Cancer Centre, or in participants’ homes. If more than one member of a family was interviewed, each interview took place separately. Children were given the option of completing their interview alone or with a companion present, a trusted adult other than the parent with whom the child felt comfortable.

Prior to beginning each interview, the process for gaining informed consent for adults and assent for children took place. This process is outlined fully in the section on Ethics in this
chapter. The Illness Time Lines were then completed by the parents and/or caregivers. For the families in which children participated in the interview process, the parent(s) completed the respective Illness Time Line while their child was being interviewed. The Worry Meters/Distress Rating Scales were completed during the interviews. Following each interview, the audio file was uploaded to Dr. Rodin’s researcher server at UHN and stored according to UHN ‘Storage, Transport and Destruction of Confidential Information' policy. Each audio file was transcribed verbatim by WordWrap Associates Inc., a transcription company in Markham, Ontario, which has an existing service provider agreement with Dr. Rodin. The transcriptions were then checked for accuracy by this doctoral candidate.

**Role of the researcher.** In keeping with Heidegger’s premise of the importance of intersubjectivity in mutual research relationships between the researcher and the participants, it is important to consider the role of the researcher. Marshall and Rossman (2011) noted, “The researcher is the instrument in qualitative studies, the presence of the researcher in the lives of the participants invited to be part of the study is fundamental to the methodology” (p. 112). Due to the nature of the subject matter and the vulnerability of the participants, an important facet of this researcher’s role was to create disclosive spaces, enabling participants to be comfortable relating details of their respective lived experiences. An additional facet of this role was captured by Charmaz who noted, “The interviewer is there to listen, to observe with sensitivity, and to encourage the person to respond” (2006, p. 25). This researcher’s clinical experience in working with children and with families coping with advanced cancer, has enabled her to develop a comfort level in bearing witness to difficult and emotional stories. Additionally, this candidate has a compassionate, empathic presence which helped to establish rapport with participants and ensure that the process of interviewing was responsive to their needs. This could be reflective of
a “sustained empathic inquiry” which Trop and Stolorow (1999) referred to as comprehending “the meaning of a patient’s [participant’s] expressions from a perspective within, rather than outside, the patient’s [participant’s] subjective frame of reference” (p. 281).

Data Analysis

“Researchers are translators of other persons’ words and actions. Researchers are the go-betweens for the participants and the audiences that they want to reach” (Corbin & Strauss, 2008, p. 49). Qualitative analysis involves interpretation and looking for clusters of meaning, assumptions, patterns, and themes to develop a rich textual restorying, true to the essence of the experiences of the participants (Cohen et al., 2000; Riessman, 2008; Thomas, 2006). As with the variety of methods for conducting qualitative research, many methods exist for analyzing the data. The following comment by Patton has relevance to this array of methods, “Because each qualitative study is unique, the analytical approach used will be unique” (2015, p. 522). In reference to phenomenological analysis, Cohen et al. (2000) proposed,

The process of analysis can be characterized as moving between two metaphors – that of a field text, constructed through the activities of data collection, and that of a narrative text, which is meant to convey the researcher’s present understanding and interpretation of the data to all other readers and which stands alone as the findings of a hermeneutic phenomenological study. (p. 71)

That being said, one uniform method of data analysis in relation to hermeneutic interpretive phenomenology does not exist. Researchers have proposed various steps or stages to facilitate the analysis in relation to this research methodology (Cohen et al., 2000; Giorgi, 2009; Moustakas, 1994; Smith et al., 2009).

Hermeneutic circle. To facilitate the process of moving toward developing a detailed understanding of the lived experiences of the participants in this study, Heidegger’s concept of
the hermeneutic circle was used to throughout the analysis. Because the interview data gained from participant interviews were rich in description and meaning, it was fitting that the analysis involved a circular and iterative process, looking at the parts, returning to the whole, and looking at the parts again. Additionally as Heidegger contended, the hermeneutic circle is inclusive of culture and history. This aspect of the hermeneutic circle is important to this researcher as culture and history can’t be separated from individuals’ stories.

To begin the circular process, this researcher listened to each audio file completely to remember each interview and the participant’s story (in addition to verifying the accuracy of the transcripts). As each was listened to, notes were made of non-verbal aspects such as pausing, inflections, intonations, and hesitations, which were helpful in the analysis (as discussed at a later point in this section). This researcher then re-read the transcripts with intent, moving from the parts to the whole and the parts again; a process that continued throughout the analysis.

**Specific method of data analysis.** Based on the literature associated with data analysis and phenomenological research, two methods were considered in reference to this doctoral study: Moustakas’s Heuristic Inquiry, a method of analysis based on a “simplified version of the Stevick- Colaizzi-Keen method” (as cited in Creswell, 2007, p. 159); and Smith, Flowers, and Larkin’s Interpretative Phenomenological Analysis, IPA, (2009). Each method involves similar steps, encompassing a reflective engagement with the data, culminating in a description of the essence of the lived experience of participants. Moustakas’ method, however, is generally associated with eidetic or descriptive phenomenology rooted in the work of Husserl, and involves aspects such as epoché, bracketing, and phenomenological reduction. The method proposed by Smith et al. (IPA) is based on the work of Heidegger and Gadamer, is interpretative
in nature, and is associated with hermeneutic phenomenology. To that end, IPA was incorporated as the primary method to analyze the data collected from the research interviews.

**Steps in the phenomenological analysis.** Smith et al. outlined steps in their method of analysis. Each is discussed in the following table, using the authors’ terminology in relation to this doctoral research. The findings of this analysis using IPA will be discussed in Chapter Five.

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<th>Steps</th>
<th>Description</th>
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<td>Step 1 – Reading and re-reading (p. 82)</td>
<td>Initially, all written transcripts were read fully to get an overall feeling for the participants’ stories, enabling this therapist to be immersed in the data. This was followed by a “reflective engagement with each participant’s accounts” involving a line-by-line analysis of the “experiential claims, concerns, and understanding of each participant” (p. 79).</td>
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| Step 2 - Initial noting (p. 83-88) | This step involved an examination of the “semantic content and language use” specifically “noting exploratory comments about anything of interest within the transcript” (p. 83). The authors proposed three categories of exploratory comments:  
1) Descriptive comments: describing the context of what the participants said; “key words phrases or explanations – things which matter to the participant” (p. 84). These were indicated in regular font.  
2) Linguistic comments: exploring the specific use of language by the participants - words used to describe experience, pauses, inflections, intonations. These were indicated in italics.  
3) Conceptual comments: engaging at a more interpretative level, “each interesting feature of a participant’s account may prompt further questions” (p. 88). These were indicated by underlining text.  
This researcher developed a table with three columns: the left hand column provided space for the original transcript, the centre column included the categories of explanatory comments related to segments of each transcript, and the right hand column provided space for notes made by this researcher. Through this process, this researcher increased familiarity with the ways the participants thought, felt and discussed the phenomenon. |
| Step 3 - Developing emergent themes (p. 91-92) | This step involved looking for emergent themes, or “mapping the interrelationships, connections and patterns between exploratory notes, paying attention to convergence and divergence” (p. 91). “Themes are phrases which speak to the psychological essence” of participants’ lived experience, and “reflect a synergistic process of description and interpretation” (p. 92). |
The authors related this stage to “Gadamerian dialogue; a process of moving between the researcher’s pre-understandings, and newly emerging understandings” (p. 88).

It was important to include the use of verbatim examples or “exemplars - textual data in the language of the informant that capture the essential meaning of themes” (Cohen, Kahn, & Steeves, 2000, p. 80).

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<th>Step 4 - Searching for connections across emergent themes (p. 96-98)</th>
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<td>In this step, this researcher wove the emergent themes together to “produce a structure that is true to all of the most interesting and important aspects of the participant’s accounts” (p. 96). The authors proposed the following to enable connections across themes:</td>
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<td>1) Abstraction – “a basic form of identifying patterns between emergent themes and developing a sense of ‘super-ordinate’ themes” (p. 96).</td>
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<td>2) Subsumption – “an emergent theme itself acquires a super-ordinate status as it helps bring together a series of related themes” (p. 97).</td>
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<tr>
<td>3) Polarization – “examining the texts for oppositional relationships between emergent themes” (p. 97), in essence looking for differences</td>
</tr>
<tr>
<td>4) Contextualization – connections between emergent themes, identifying contextual or narrative elements within an analysis – attending to temporal, cultural and narrative themes</td>
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<tr>
<td>Putting it together – this researcher developed a “graphic representation of the structure of the emergent themes” (p. 99).</td>
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<th>Step 5 – Moving to the next case</th>
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<td>The process outlined in Steps 1 – 4 was repeated with each transcript, treating each transcript “on its own terms, to do justice to its own individuality” (p. 100). New emergent themes, in addition to divergent themes, were noted.</td>
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<th>Step 6 - Looking for patterns across cases</th>
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<td>In this step, this researcher looked for connections between themes and transcripts. The authors indicated, “pointing to ways in which participants represent unique idiosyncratic instances, but also shared higher order qualities” (p. 101).</td>
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Although the authors indicated that this step is usually outlined in a table, this researcher felt it was important to provide an in-depth thick description of the themes within and across cases, illuminating the essence of the phenomenon or participants’ lived experience.

In summary, the intent of this analysis was to gain a detailed understanding of the lived experiences of participants, reflective of the complexities of parents’ advanced cancer. These two facets, the hermeneutic circle and an interpretative phenomenological analysis, facilitated an analysis that “constitutes reading, reflective writing and interpretation in a rigorous fashion” (Laverty, 2003, p. 195).
Strategies for Rigor: Trustworthiness

In qualitative research, minimizing or avoiding bias can be achieved through rigor; authenticity of the findings and credibility of interpretations (Creswell, 2007). “The goal of the hermeneutic phenomenological researcher is to be able to report things as they appear to be as encountered in the field and documented in the field text, rather than as the researcher would have them be” (Cohen et al., 2000, p. 86). Trustworthiness is the most important facet in achieving rigor. Trustworthiness in this study was established through five of the six strategies for enhancing rigor as indicated by Padgett (1998): prolonged engagement, triangulation (theory and data), peer debriefing and support, member checking, and an external audit. As there were no negative cases in the findings, the strategy of negative case analyses was not incorporated.

Prolonged engagement is essential in establishing the researcher’s credibility in relation to an integrated knowledge of the research focus (Padgett, 1998). It is related to the duration of time spent by the researcher in the field of study. In addition to more than 35 years of experience working with children and families, this doctoral candidate has over 15 years of experience directly related to oncology and palliative care, specifically working with children and families coping with end-stage cancer. Furthermore, the research for this doctoral study was conducted over 32 months (May 2014 to December 2016). This researcher conducted one hour interviews with each parent or caregiver, and in some cases, with the child (or children) in the family, which enabled a strong connection with the respective families, adding to the integrated knowledge. Each aspect provided the researcher with prolonged engagement with the research population.

Triangulation refers to the incorporation of diverse sources of data to gain a comprehensive understanding. Theoretical triangulation was achieved through the use of more than one theory to inform the study. This helped to ensure that the data were conceptualized from different perspectives. Triangulation of the data was attained through the use of several sources to ensure
richness in the analysis and results. An additional form of triangulation involves the use of a range of informants (Lincoln, 1995). As the interviews involved ill parents, well parents and children from diverse backgrounds, this supported triangulation of data.

With regard to peer debriefing and support, this doctoral study was associated with the three studies conducted by Dr. Rodin’s research team at the Princess Margaret Cancer Centre. This doctoral candidate had the opportunity to debrief with researchers at the Princess Margaret Cancer Centre. An additional avenue for debriefing and support represented the members of this candidate’s doctoral committee, who hold expertise in areas related to this study.

A further strategy to ensure trustworthiness is member checking or discussing the research with participants to determine the accuracy in capturing the essence of their experiences. This can be established through discussion of the research findings following analysis. As some of the ill parents died following their respective interviews, however, completing member checking in this way was not realistic. As a result, another method of member checking was employed during the data collection phase. In their discussion of rigor in qualitative social work research, Barush, Gringeri and George, (2011) indicated that member-checking can be incorporated to “deepen the understanding rather than as a corroborative strategy” through “listening deeply and raising questions with participants to clarify thoughts, which will strengthen their findings” (p. 13). During the interviews, this researcher listened intently and empathically to the participants’ stories and asked questions to clarify, as needed.

Finally, an audit trail was maintained through electronic patient records, interviews, audio files, transcriptions, and an account of decisions made to ensure that another researcher would be able to replicate the study, achieving similar research findings.
Ethical Considerations in Research

“Ethical issues and challenges are located in the space between researchers, research organizations, children, parents/caregivers/guardians, communities and others involved in the research process” (Graham et al., 2013, [ERIC], p. 26). Researchers have a fiduciary responsibility to address any ethical considerations with research that involves human participants. Ethical considerations can be significant when research involves vulnerable populations, such as the children participating in this doctoral study. Mishna et al. (2004) indicated, “Research with children in general and qualitative research with children in particular has the potential to present unique ethical issues for the researcher” (p. 450). The following section will provide details of the ethical considerations associated with this doctoral research. Aspects of the detailed Study Protocol approved by the University Health Network Research Ethics Board, Princess Margaret Cancer Centre and the University of Toronto Research Ethics Board Administrative Approval of the Study Protocol will be incorporated into the discussion.

In Canada, the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2), (Canadian Institutes, 2014) represents the primary document governing the ethics involved in research with human subjects. This document was consulted during the proposal phase of this current research. The TCPS2 outlines the core ethical principles of respect for persons, beneficence, and justice are integral aspects of all research. These core principles will be discussed in relation to this doctoral research. Mishna and colleagues (2004) noted,

In demonstrating respect for these principles researchers must: (1) seek informed consent to participation; (2) minimize discomforts and harm to participants and ensure that on balance the research brings about a good; and, (3) ensure that participants are fairly
selected and that the burden and benefit of research is fairly distributed among members of the population. (p. 452)

**Respect for Persons**

The TCPS2 denoted this core principle as “the intrinsic value of human beings and the respect and consideration that they are due” (2014, p. 6). Respect in research encompasses the procedures for providing individuals with opportunities to make fully informed decisions about participating in research, as in the process of informed consent and/or assent. This is particularly important for vulnerable populations as researchers have “dual moral obligations to respect autonomy and to protect those with developing, impaired or diminished autonomy” (TCPS2, 2014, p. 6). The process of informed consent and/or assent with the participants of this study was complex, due to the multiple types of potential participants; adults, adolescents seventeen to eighteen years, children six to sixteen years, and adult companions (to support children if they wished to have a trusted adult present in the interview).

**Process of informed consent and/or assent.** “Freely given informed assent/consent is the cornerstone of contemporary clinical research ethics” (Helseth, & Slettebø, 2004, p. 302). The following sections provide information regarding this process as outlined in the Study Protocol.

**Informed consent for parents.** This doctoral candidate reviewed the parameters of the study with patients and well parents or caregivers, either in person following an appointment at Princess Margaret Cancer Centre, or by telephone. Prior to the respective interview with each participant, a copy of the Informed Consent Form for Parents (Parents Living with Cancer, and Well Parents or Caregivers) (Appendix F) was reviewed in full together with this doctoral candidate. Sufficient time was provided to answer all questions to ensure participants fully understood the study, especially their right to participate in, and withdraw from, the study as they
saw fit. Each participant knew that his/her participation was fully voluntary, and that he/she could chose to answer, or not answer, any question, or stop the interview at any time. The Informed Consent Form was then signed, witnessed, dated and a copy was given to the participant for his/her records.

**Informed consent for children seventeen and eighteen years of age.** According to the Research Ethics Board of Health Canada, children 17 and 18 years are considered “mature minors” and are eligible to consent to participate in research (Government of Canada, 2014, para. 2). This doctoral candidate, therefore, received ethics approval to follow the same process for gaining consent for patients and well parents/caregivers (described above) with children in this age group. A copy of the Informed Consent Form for Children (17 to 18 years of age) (Appendix G) was developed and approved to review with each potential participant. During the time of data collection, none of the study participants were 17 or 18 years.

**Assent for children six to sixteen years of age.** “In Canada, consent procedures are governed by common law and, with the exception of two jurisdictions, there is no specific legislation governing consent practices with children. Thus, in Canada consent procedures are governed by capacity” (Mishna et al., 2004, p. 545). Capacity can be seen as an individual’s ability to understand the information provided to make an informed decision about a given circumstance. Higgins noted, “The capacity to make voluntary, informed decisions evolves throughout childhood and adolescence and varies among individuals of the same age” (n.d., para. 5). Assent pertains to the process of providing a child with the details of a study “in a manner tailored to the child’s ability to understand; soliciting his or her assent for participation; and respecting dissent” (Centre of Genomics and Policy, 2012, p. 21).
During the recruitment phase, when this doctoral candidate spoke with parents about the study, and in particular the involvement of children, they were made aware of the assent process as it related to the participation of children. If a child wished to participate, prior to the scheduled interview, the parent’s consent was sought for their child (children), six to sixteen years of age, to participate and the parent was provided with a copy of the Information and Assent Form for Children (Appendix H). Sufficient time was provided for a parent to ask questions ensuring he/she understood the study as it related to the participation of their child. This doctoral candidate then met with the child and the patient and/or parent or caregiver to discuss the study parameters. The Information and Assent Form for Children was reviewed with the child ensuring he/she also had sufficient time to ask questions and that their concerns were answered. Once the child indicated that he/she understood the study and their participation, his/her assent was sought verbally. Patients and well parents or caregivers were present when the study was explained to the child. When the child verbally assented to participating, the patient and/or parent or caregiver was asked to sign and date the Information and Assent Form for Children. Copies of the signed, witnessed and dated assent form was provided to parents.

Informed consent for Adult Companions. To further demonstrate respect, a child could request to have an adult companion present with him/her during the interview, a trusted adult other than the parent with whom the child felt comfortable. As indicated previously in this chapter, this option was discussed with the parent or caregiver during the initial recruitment phase. If a child was to make such a request, the identified companion would meet with this doctoral candidate to discuss his/her role as a non-participating companion while the child was taking part in the interview, and to review the Informed Consent Form for Adult Companions.
(Appendix I). No children who participated in the study, however, requested to have an adult companion present in their respective interviews.

**Beneficence – Concern for Welfare**

“Concern for welfare means that researchers and REBs should aim to protect the welfare of participants, and, in some circumstances, to promote that welfare in view of any foreseeable risks associated with the research” (TCPS2, 2014, p. 8). Researchers have a fiduciary responsibility to balance potential benefits and minimize risks to participants, and to clearly inform participants of specific benefits and risks involved in participating in the study.

**Risks to participants.** A potential risk was that participants discussing or disclosing emotionally sensitive details could experience feelings of distress. Patients and well parents or caregivers were made aware of this risk for themselves, and the children, if they chose to participate. Accessing supportive services, if needed, was also discussed. Such services could be available through the patient’s oncology clinic, and the Department of Supportive Care at the Princess Margaret Cancer Centre. Additionally, parents were made aware that if they or their child needed further support, referrals could be made through regional children’s mental health agencies, family service agencies, or licensed /registered private practitioners. During, and following, the interview phase, no participants requested such services as a result of the disclosure of emotionally sensitive details of their respective situations.

**Benefits to participants.** Although participants may not have benefitted directly from participation in this study, the information collected will benefit children and their parents / caregivers in future. The detailed understanding gained will inform social work practice and education, and could support agencies in the creation of developmentally appropriate child and family centred short- and long-term support strategies. Such strategies will assist immediate
support systems and communities in better meeting the needs of children and families experiencing the distress of advanced cancer, and the uncertainty of shortened life expectancy. Moreover, this understanding has the potential to encourage policy and service revisions, thereby enabling families and professionals to create safe spaces for children during this sensitive time.

An additional potential benefit may lie in the opportunity for children’s voices to be heard. “Children shall not be inappropriately excluded from research solely on the basis of their age or developmental stage” (TCPS2, Article 4.4, p. 52). Often children are not given a chance to tell others how they feel, and to express the issues with which they need help, related to what is happening to their parent. The increased understanding of the meaning of the experience of children represents potential benefits to participants.

**Specification of safety parameters.** As outlined in the approved Study Protocol, the following parameters of safety were specified. As this study involved qualitative interviews, it did not affect the patients’ care at the Princess Margaret Cancer Centre. If, during an interview, it was determined that a child was at risk of self-harm, or he/she had been harmed physically, emotionally or neglected, this doctoral candidate was required to inform Children’s Aid Society as duty to report. Finally, if suicidal intent was revealed by a participant, Dr. Rodin would be contacted immediately by phone or pager, or if unavailable, the psychiatrist on call at the Department of Supportive Care, for guidance, and if necessary an emergency assessment.

**Confidentiality.** “Other contributing factors to welfare are privacy and the control of information about the person” (TCPS2, 2014, p. 7). In discussing consent, this researcher ensured that confidentiality was understood both by the parents and children. Confidentiality was maintained throughout the process. Participants’ names and any identifying information were not
used on any documents with the exception of the study recruitment Source Notes (Appendix S). Personal identity or information will not be released or printed at any time.

**Storage and protection of confidential research material.** All written information and digital audio recordings are kept in password protected files stored according to UHN ‘Storage, Transport and Destruction of Confidential Information' policy: as electronic files on study-specific network drives, folders or intranet sites on a secure UHN network or, temporarily, on an encrypted biometric USB key or an encrypted computer or digital audio-recorder. As this study did not involve a clinical trial, all records and documents pertaining to the study will be retained by the study trial site at UHN for at least ten years from the completion of the study after which time they will be destroyed. The audio-recordings will also be stored at UHN for ten years from the study completion.

**Justice**

As defined by the TCPS2, this core principle refers to:

The obligation to treat people fairly and equitably. Fairness entails treating all people with equal respect and concern. Equity requires distributing the benefits and burdens of research participation in such a way that no segment of the population is unduly burdened by the harms of research or denied the benefits of the knowledge generated from it. (2014, p. 8)

An important research issue related to justice is that of potential power differences between adults (the parents and researcher) and children, recognised as “one of the biggest ethical challenges for researchers seeking to include children in research” (Centre of Genomics and Policy, 2012, p. 41). With the current study, this doctoral candidate’s diverse experience with children has provided her with critical awareness of the potential for such power imbalances, and the importance of viewing children as social agents whose voices should be respected and
honoured. This clinical experience supported an awareness of interviewing children, noting actions, and verbal/non-verbal cues by children to indicate aspects such as discomfort. Kirk (2007) outlined strategies to manage potential power differentials between children and researchers, three of which were incorporated by this researcher: (1) checking on children’s willingness to participate throughout the interview (including being aware of nonverbal cues such as body language); (2) rehearsing with children how to decline participating or answering particular questions; and (3) in interview studies giving children control over tape recorders. With the last strategy, each child was able to test the voice operated recorder prior to the interview starting, in addition to checking on the recorder during the interview to ensure it was working, something each child enjoyed doing.

**Summary and Conclusion**

This chapter outlined the research design and methodology for this research. A discussion of the specific methodology used, hermeneutic interpretive phenomenology informed by Heidegger and Gadamer, was presented. The specificities of the research design and analysis were discussed in detail. Strategies to ensure rigor in qualitative research were then outlined. The final section of the chapter addressed ethical considerations. Chapter Five presents the research findings based on this research design and methodology.
Chapter 5
Research Findings, Analysis and Interpretation

The focus of this chapter involves a presentation of the research findings which will enhance the understanding of the lived experiences of children and parents coping with advanced cancer. To begin, a brief description of the participant families will be provided, supplemented with exemplars from transcripts and documentation from the reflective journal kept by this doctoral candidate. The research findings will then be presented through discussion and the inclusion of further exemplars. As indicated in Chapter Four, the process for analyzing and interpreting the data followed Smith, Flower, and Larkin’s Interpretive Phenomenological Analysis (2009). The steps in this method will be discussed, leading to the formation of themes. This discussion will enable the various threads of participants’ stories to be woven together to provide a rich understanding of the phenomenon through (1) the parents’ perspectives; (2) the parents’ perspectives of their children’s experiences; and (3) the children’s perspectives.

The Participant Families

Seven families participated in the research. In this section, each family will be introduced, providing details regarding the parent living with cancer, the well parent, and the children. As this researcher was unable to sample theoretically, it is important to note the homogeneity of the sample. The parents were married, heterosexual, white, and professionals living and working in the greater Toronto area. This represents a limitation to the study which will be discussed further in Chapter Six. In relation to a homogeneous sample, however, Smith et al. (2009) noted, “IPA studies are conducted on relatively small sample sizes, and the aim is to find a reasonably homogeneous sample, so that, within the sample, we can examine convergence and divergence in some details” (p. 3). Moreover, diversity was represented in the following aspects: gender (ill
parents were male and female), age (ranging from 39 to 59 years), ethnicity (two parents who were new to Canada as young adults), and religion (agnostic to observing religious practices).

Additional aspects pertinent to the introduction of families relate to the location of the interviews, and the way in which members of the family were identified. As this researcher endeavoured to ensure that the interviews took place in disclosive spaces in which participants felt comfortable, participants chose to be interviewed in their home or in a quiet space at Princess Margaret Cancer Centre (PMH). With respect to the identification of family members, the following were used: PC – parent with cancer, WP – well parent/ caregiver; CD – child.

Finally, although the parents living with advanced cancer knew they were going to die, the circumstances of their respective disease trajectory were reflective of two states as proposed by Teno and Coppola (1999), “persons who are ‘living with a life-threatening illness’ and those persons who are ‘actively dying’” (p. 110). This distinction is reflected in the narrative accounts and the analysis and interpretation.

**Family 1** (PC 1, mother; and WP 1, father)

Family 1 comprised a mother and father (in their early 50s) and 18 year old triplets. Although both parents were professionals at the time of the interviews, the mother was no longer actively working. The mother was initially diagnosed with an abdominal sarcoma in 2007. Treatment involved radiation, followed by surgery to remove several abdominal organs. The couple was told by the oncology team that they were confident about her prognosis, “*They thought they could cure me.*” Within two and a half years, however, the cancer had returned to her lungs and she began chemotherapy. From that time, on-going treatment involved different kinds of chemotherapy, with the hope that each would shrink tumours and prevent further
metastases. She related that one year ago, the cancer had spread to her pancreas and liver. At the
time of the interview, she was on a clinical trial which was her last option.

When this researcher spoke with the mother about participating in the study, she was very
receptive and stated that her husband and children also wanted to participate. A date was set for
the interviews with the mother and father. Due to her declining health, the interviews took place
at their home. It was planned that the interviews with the children would take place later in the
summer as they were working at a camp. Upon arriving at the home, the mother was sitting on
the couch propped up with pillows, wrapped in a blanket (it was a warm summer day). She
appeared unwell as she was thin, gaunt, and her movements were laboured and slow. Her voice
was weak, but she was trying to sound strong. Before the interview, her face looked sad and she
paused as she related that she was struggling with her cancer. As the interview began, her
sadness faded and she spoke in a matter of fact manner when discussing her cancer. She related a
great deal of medical details in a frank tone, which this researcher felt may be reflective of her
profession. Her sadness returned, however, when she discussed points such as the meaning of her
declining health for her and for her family, potentially reflective of a mother and wife struggling
with the end of a long cancer journey. This shift between her professional and personal tones was
evident when describing the recent metastases, “I’m a [name of profession], and so I know about
cancer. And so I just felt like I was dying. I remember walking around thinking this is the end of
my life and what it would feel like if I was dead.”

During the interview with the father, the worry and drain of the chronicity of his wife’s
cancer, compounded by caring for her and for the children, was evident on his face which looked
drawn and weary. He spoke with a firm tone and frankly about the situation. At times there were
pauses as he collected his thoughts, reflecting on the situation. He related details about his wife’s
cancer that were similar to those related by his wife. While he answered the questions and discussed the progression of the situation over the years, a thread of what he called a “double life” permeated through the discourse. This focused on the relentless nature of his wife’s cancer, along with her ardent need to be positive above all else. This was depicted as he related the hardest part of the situation, “There’s not one moment, but this general theme about this ongoing double life that I lead, which is what I tell my friends. ... That’s been going on for seven years, well, intensively for probably four or five years.” Reflecting on the reality that his wife would not survive much longer, he said being unable to talk about this complicated things because he could not support her in dying, or support the children. The interview ended with discussion of meeting the children at the end of the summer. Sadly this mother died a few weeks later.

**Family 2** (PC 2, father)

This participant family comprised two parents (mother and father; in their early 50s) and two children (son, 13 years, and daughter, 15 years). Both parents were professionals, and at the time of the interview however, the father had recently stopped working. The father indicated he was an immigrant, coming to Canada as a young adult. During the course of the interview, he also stated he was agnostic. This father was diagnosed with advanced prostate cancer with metastases to the bones in 2011. He said the diagnosis was a complete shock as he had not experienced any symptoms and was in good health. He went to his family doctor because of back pain, which he thought was from heavy lifting he had done. When this researcher spoke with this father about the study, he expressed interest in taking part, and he felt that his wife and one of his children would also want to participate. It was agreed that this researcher would meet with this father at PMH, and the interviews with his wife and child would take place at their home.
This father presented as a strong individual, who spoke with conviction throughout the interview. His love of life was evident, as he giggled while relating stories about his life, and his family. The sadness he was experiencing at the lack of success with treatment, aggressive cancer, anticipatory grief of the loss of his own life, and the effect of this on his family, was expressed nonverbally through extended pauses, and a different giggle. An example was his comment regarding the lack of success with treatment,

“It’s always bad news and then go into a new treatment. I haven’t had good news, I don’t know, in a year and a half now. That’s the toughest part. I think, doing all this stuff, taking all these drugs, and it’s not working. That’s the toughest.”

At the end of the interview, he smiled and said, “We’re a close family, not a perfect family, but a very loving family. Cancer hasn’t taken that from us.” As agreed, this researcher contacted this father later in the summer to set up a time to meet with his wife and children. He indicated that his situation had changed again, and his wife and children felt they were unable to participate.

This father died several months later.

**Family 3 (PC 3, father)**

This family comprised two parents (a father and mother, in their late 50s), and two children (16 year old son, and 13 year old daughter). Although both parents were professionals, at the time of the interview, the father no longer worked full time, but rather, in a consulting role. This father was diagnosed with advanced prostate cancer in 2006, which spread to his bones. The diagnosis was a complete shock as he was healthy prior to diagnosis. This father expressed interest in participating in the study, however, his wife and children were not able to participate. The interview with this father took place at PMH. This father spoke in depth about living with cancer for several years while remaining active professionally, and personally as a husband and father. His attention to detail was notable for this researcher, which perhaps was an aspect of his
professional role. Although he, too, experienced bad news about his cancer, this father spoke with a sense of calm. When talking about the meaning he made of cancer, he discussed his reflections and the positives for his family, while coming to terms with his eventual death,

*I assumed I was going to die, relatively soon. Without knowing what relatively soon meant…. I think I've enjoyed the last nine years more than I would have otherwise. Besides the cancer, that's always in the back of my mind, and a bit of a cloud."

He stated there was a chronicity to his cancer, and although he was terminally ill, it was “life as usual” for the family. He indicated there were stretches of quiet when his cancer was managed by treatment, interspersed with turmoil of bad test results and a narrowing of options. A year earlier, he was told he had one to two years to live. He and his wife had a conversation with their children, who were approximately 15 years and 12 year at that time, and related this to them. As will be discussed in the analysis and interpretation, although this represented a conversation a parent should never have to have with their children, this father indicated it served to draw his family even closer.

**Family 4 (PC 4, mother, WP 4, father, and CD 4, son)**

This family represented the youngest family in the study, with parents in their 30s (mother and family), a six year old son and a 4 year old daughter. Both parents were professionals, however, the mother was no longer able to work at the time of the interview. The mother was initially diagnosed with stage 2 breast cancer two months after the birth of her daughter. Two months later the diagnosis was changed to stage 4 advanced triple negative breast cancer, with metastases to her lungs and bones. For this young couple this news was devastating. The sadness of the situation was expressed as she commented,

*I'm going to die young. That's the hardest part ... I'm going to die this year sometime, so... That's, that’s my hardest challenge. That I won't be there to, to, um... take care of my children.*
The cancer spread to her brain, recurring twice. Their lives have been filled with repeated bad news, failed treatments, radical brain surgery, and a life turned upside down.

Upon meeting this mother, it was evident that her body was very compromised by cancer. Her walking was laboured, and she was quite fatigued. Her voice was weak and she stopped her conversation repeatedly to gather her thoughts, and/or to gain some strength to continue. Her struggles with word retrieval and losing her train of thought were evident, which frustrated her. Additionally, she had a noticeable tremor in her head and hands, periodically holding her hands to calm the tremor. She spoke at length about the effect of her cancer on her ability to parent her children, relating that the diagnosis came at a time when she should be enjoying her newborn and toddler. Instead she had to cope with the effect of long term treatment which greatly compromised all aspects of her life. This mother concluded her interview with the following,

*I think one of the things that's, um, is... an interesting thing is that my idea of quality of life has changed because of, because of, um, cancer. Um, I would choose length of time to meet milestones as a quality of life length, length of time over quality of life. So I would choose just to live longer, and be not as healthy, um, over living a short time and being, being healthy. I had to clarify that with my oncologist. I had to tell him that my, my goals are to live as long as possible, to meet milestones, not live the best quality of life. So trying to meet, you know get to [daughter’s name]’s first day at take her at, ah, to kindergarten.*

The intensity and chronicity of living as the husband of a mother dying from advanced cancer, and a father of two young children, was evident in the interview with this father. His face was worn with fatigue and a seriousness was present, echoed by his comments that they were too young to live this life. Initially he discussed his wife’s cancer with similar facts provided by her. He, however, went into a level of detail than his wife was unable to do. He spoke about the effects of cancer and treatment on his wife, their relationship, and on the children. As she was physically compromised for some time, this father took on all the parenting and household tasks,
in addition to caring for his wife, all the while trying to work full time. The unfairness and frustration of the situation permeated the disclosive space as the following typified,

You know, I’d say that, you know, uh, we’re kind of in that phase of parenting. And I can see this by our friends and family who are out there as well, who have a couple kids and they’re in their thirties, and they’ve got a mortgage, and they’re trying to work, and they’ve got a lot of stress. And, um, when you add cancer on that, particularly, metastatic or advanced cancer, it really kind of, it changes your perspective greatly. It makes it a lot, not worse, but harder and frustrating for all of us - you just kind of cope and survive.

The son was a dynamic six year old boy with blue glasses, who, after meeting with this researcher, decided to participate in an interview. Prior to beginning the interview, this researcher demonstrated how the audio recorder worked and invited him to make sure that the ‘bar was jumping as we talk so we know it is working.’ This was a job he delightedly took on, continually pointing to the bar as he talked. Sitting on his knees to be able to reach the table and colour, he held his own in the interview, ensuring that this researcher understood the thoughts and feelings he was conveying. He readily discussed his mother’s cancer, and the fact that he knew she was going to die. It was evident that he was trying to understand what that would mean for him, relating connections he was making, as seen in the following, “There’s, there’s something that I watched. And it’s about somebody’s mom dying. It’s about like (... pause, thinking) Harry Potter’s mom and dad died.”

**Family 5 (PC 5, mother, and CD 5, daughter)**

This family comprised two parents (mother and father; in their late 40s) and their daughter (9 years). Although both parents were professionals, at the time of the interviews the mother was on a leave of absence from work. When this researcher spoke with this mother about the study, she stated that she and her daughter would like to take part, however, her husband was unable to participate. The interviews took place at their home.
This mother was diagnosed with melanoma in 2012, with a recurrence and metastases to her lungs. Through failed treatments, significant side effects, negative results of tests, and recurrence, she stated, “I just felt like I was constantly going through this, uh, revolving door.” Following the metastases to her lungs, she discussed the despair she experienced as a mother living with dying. This mother also voiced a strong sense of guilt at the diagnosis. She said her cancer was a result of lifestyle choices in her early life. Despite her oncologist saying the contrary, this mother struggled with the notion that her life could be very different had she, her parents, and society known about the effects of the sun. Cancer permeated all aspects of her life, as she stated, “I had a PICC line put in on my birthday. ... Happy Birthday to me.” Cancer also affected her marriage, which saddened her, “I could see a change in my... in my marriage ... and my husband was very not... non-active in the whole year that I...He was just very absent.”

With regard to her daughter, this mother tried to protect her daughter from the full realization of her cancer. Being very close to her daughter, she voiced that she wanted life to be as normal as possible, and not burden her daughter. This was evident during the interview with her daughter. Although initially hesitant, she readily became comfortable and helped this researcher understand what her mother’s cancer meant to her. She was keen to watch the audio recorder to ensure it was working properly, and she wanted to draw during the interview. What was most apparent was her ability to see her mother first and foremost, and cancer second. While discussing her worry for her mother because of all she had been through, she related, “I worry about her. ... but I don’t feel so worried at school, because I know she’s a strong woman.”

**Family 6 (PC 6, mother, WP 6, father)**

This participant family comprised two parents (mother and father) and an 18 year old son. Both parents were professionals. At the time of the interviews, however, both were on leave from
their jobs, in order for the husband to care of his wife while she was undergoing treatment. The father related that he was an immigrant, coming to Canada as a young adult. Both parents indicted that their son was traveling and could not participate. This mother was diagnosed with advanced metastatic ovarian cancer one year prior to the interviews. As with the other participants, the diagnosis was completely unexpected. Her story, however, regarding the diagnosis was different from the others. She equated the process spanning several months to “½ and ½ (it was, it wasn’t ... it was)” as she was initially undiagnosed, then misdiagnosed, with differing opinions from specialists. With the realization that it was stage four advanced cancer, the couple was devastated. She related in the initial phone call, “my world as I knew it ended. The life that I thought I was going to have ended that day. It was not to be.” Following diagnosis, she received aggressive treatment, which resulted in significant complications. During that time, she could not bring herself to talk to anyone, family, friends, or colleagues as it made it too real, “I’m very social, but I had completely blocked myself out from everyone.” This mother also briefly discussed the importance of her faith, helping her come to terms with her cancer.

Initially hesitant to participate because it was difficult for him to talk about his wife’s cancer, this father wanted to support his wife, and other husbands/fathers in this situation. In relating the details of his wife’s diagnosis and treatment, he echoed her comments. His concern for her was evident on his face as it looked drawn, and nonverbal aspects such as voice tone and pauses, particularly as he discussed the reality of the situation, “Her chances of surviving for many years is not very high.” An additional point of discussion focused on the emotional drain he had experienced. This drain stemmed not only with his wife’s cancer, but also as he has experienced 18 deaths in 2 years, including his mother, cousins, and friends, many of whom also died of cancer. In essence, the chronicity of cancer was a pervasive part of his life.
Family 7 (PC 7, mother, WP 7, father, CD 7a, daughter, CD 7b, son)

The seventh family was comprised of two parents (mother and father in their early 40s) and two children (a daughter 11 years, and a son 9 years). Both parents were professionals, however since her diagnosis, the mother was on leave. This mother was recently diagnosed, in the early fall, with pancreatic cancer. The family was shocked by the diagnosis, as she was in good health and sought medical support for a gall stone. During the ultrasound, the tumour on her pancreas was found. At the time of the interview she had started chemotherapy. Treatment would then involve surgery to remove the tumour, followed by radiation. If the chemotherapy was not successful, an option discussed would be the removal of her pancreas and living as insulin dependent for the remainder of her life. As the situation was so unexpected for her family, this mother was most concerned about her children. She related in the initial phone conversation that she continually worried about her future as their mother in a different way than she has since she became a mother. When she spoke to her husband and children about the study, they said they wanted to participate. It was agreed that the interviews would take place at the family’s home.

During the interview with this mother, the fear of the situation was clear in her verbal and nonverbal presentation, as she spoke quickly, giving a lot of detail, with a nervous giggle. The theme that pervaded the interview was this mother’s need to “keep our family’s life as routine as possible, I don’t want too much to change.” As she related her story, it became rapidly clear that consistent family routine would likely be possible due to the size of the extended family who actively took on specific helping roles. Finally a deep faith anchored this family.

The daughter presented as competent, and readily spoke about her mother’s recent diagnosis and what this meant to her, to her mother, and her family. She emulated her mother in her nurturing, positive outlook, and faith. The following typified her comments in the interview,
“because if you’re just negative and miserable all the time you’re just making things worse. So I think being positive and strong, um, lifts your spirits up and you won’t worry as much.” Woven through the interview was the importance for this pre-teen to talk to other children her age who also have a parent living with cancer, “who understand and knows how you’re feeling.”

The son presented as thoughtful, shy and soft spoken, however, during his interview his comments helped this researcher to understand what he thought and felt about his mother’s recent diagnosis. His primary concern was potential hospitalization for his mother, and how the cancer and treatment may change her. “...That she would have to stay in the hospital for a long time ... I wouldn’t get to see her.” Contrary to his sister, he said he did not think he wanted to talk to other children who have a parent with cancer. He felt he could talk to his family, and significant adults in his world, such as his hockey coach.

The interview with the father took place at a later date at PMH while his wife had an appointment. The shock and unexpectedness of his wife’s diagnosis was the focus of the initial part of the interview. He related details similar to those related by his wife, however, he added his strong sense of helplessness, “I guess there’s just a feeling of, I guess helplessness, you know, and just my thoughts go, you know, definitely with [wife’s name], but then right away go to the children.” This father spoke several times about the realization of the magnitude of pancreatic cancer and the eventual reality that his wife may succumb to this. On one occasion he stated, “Although there is, I mean, everyone says, okay, be optimistic and be... think positive. It’s difficult when you’re faced with what it is, because there’s not a lot of positive... positives when it comes to pancreatic cancer.” Finally, the closeness of this immediate and extended family was apparent during the interview, which he felt was beneficial for his wife and children.

Table 6 on the following page provides a summary of the participant families.
<table>
<thead>
<tr>
<th>Family 1</th>
<th>Family 2</th>
<th>Family 3</th>
<th>Family 4</th>
<th>Family 5</th>
<th>Family 6</th>
<th>Family 7</th>
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<tbody>
<tr>
<td>Mother (52)</td>
<td>Father (52)</td>
<td>Father (59)</td>
<td>Mother (39)</td>
<td>Mother (49)</td>
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<td>Advanced, metastatic breast cancer</td>
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<td>Bones</td>
<td>Lungs, bones, brain</td>
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<td>Lungs, pancreas, liver</td>
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<td>Treatment: Surgery Hormone therapy Chemotherapy Radium injections</td>
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<td>Father (54)</td>
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<td>Father (36)</td>
<td>Did not participate</td>
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<td>Father (45)</td>
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<td>Triplet (18)</td>
<td>Daughter (15)</td>
<td>Son (16)</td>
<td>Son (6)</td>
<td>Daughter (9)</td>
<td>Son (18)</td>
<td>Daughter (11)</td>
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<tr>
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<td>Did not participate</td>
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<td>*Interviewed: Yes</td>
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<td>Did not participate</td>
<td>CD 7a</td>
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<td>Daughter (4)</td>
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Analysis and Interpretation of the Data

In keeping with hermeneutic interpretive phenomenology, this section will focus on the process of analyzing and interpreting the data as represented in the narrative accounts from participants, bringing together their understanding of the phenomenon. Gadamer proposed that as interpretation is always an evolving process, a definitive interpretation is likely never possible (as cited in Laverty, 2003). Gadamer also indicated that the fidelity of interpretation to the meaning of the text [participants ‘stories] is paramount (Gadamer, 1976). As outlined in Chapter Four, the method used to guide the analysis was Interpretative Phenomenological Analysis (IPA) developed by Smith, Flowers, and Larkin (2009). The analysis and interpretation of the data will be interwoven as each step is outlined, and will deepen with the discussion of themes and subthemes in the following section, thereby moving toward an increased understanding of the lived experiences of the participants.

While engaged in the analysis and interpretation, this researcher envisioned the creation of a tapestry. During the process of working through the analysis with the individual transcripts, the threads of each participant’s story (essence of his/her reality) became apparent. Examples of threads were those of unfathomable sadness at the loss of one’s own life or the loss of a partner or parent’s life far too soon, or threads of nurturing and love found in the closeness of family relationships. Participants’ threads were represented by exemplars included in the discussion of themes and subthemes. As the analysis progressed across the transcripts, the threads of the participants were drawn and woven together in a tapestry. These threads had similarities and differences and were represented in the map of themes and ensuing discussion.

In addition to the analogy of the tapestry, this researcher was also transformed through the process of the analysis and interpretation. Using the Hermeneutic Circle and the steps in IPA, this researcher developed an in-depth and intense involvement with each story/transcript,
becoming very connected to the details. Each transcript took on a meaning of its own for this researcher, who felt a sense of honour to be trusted with what could be considered intimate details of such a heart wrenching time for the participant families. In that light, it was important for this researcher to focus on the subjectivity of the participants, and create a representation of how they spoke their truths, the essence of their realities.

**Step One – Reading and Re-reading**

This step involved an immersion in the data to engage with the meaning of the texts and to enable a preliminary interpretation (Ajjawa & Higgs, 2007). The audio file of each interview was listened to in its entirety. This was a valuable step as it brought this researcher back to the actual time of sitting with each participant, bearing witness to detailed aspects of each participant’s story. Each audio file was listened to again as this researcher reviewed the corresponding transcript. Gadamer (1990) contended, “The researcher must take care not to be totally reliant on the written transcript, but to read these while listening to the words on tape where the two partners are working together to create a common understanding” (as cited in Fleming, Gaidys & Robb, 2003, p. 117). This process enabled verification of the transcripts, and a noting of significant moments.

Smith and Osborne (2003) noted, “Each reading has the potential to throw up new insights” (p. 67), which this researcher experienced repeatedly with each transcript. The initial immersion with the audio files and transcripts was followed by this researcher’s engagement with each participant’s story, involving a line-by-line analysis of the “experiential claims, concerns, and understanding of each participant” (Smith, et al., p. 79).

The reading of, and reflective engagement with, each transcript facilitated the hermeneutic circle. This involved initially going through the data and through it again several times, moving
back and forth between the whole, the parts and the whole again. Phrases, sentences, and topics were considered parts of each participant’s story, which were considered to be the whole story or transcript. In turn, each story was considered to be part of the collective whole, all participants’ stories together. The continual circular process facilitated this researcher’s deep engagement with the participants’ stories, creating depth and breadth to the analysis and led to the uncovering of new understandings.

**Step Two - Initial Noting**

Step 2 in this interpretive analysis involved “an examination of the semantic content and language use” within transcripts, in conjunction with “noting exploratory comments about anything of interest” through which a deeper understanding of the participants’ stories was developed (Smith et al., 2009, p. 83). As outlined in Chapter Four, the authors proposed the following categories of exploratory comments which were used in the analysis:

1. Descriptive comments: describing the context of what the participants said; “key words phrases or explanations – things which matter to the participant” (p. 84).
   - This researcher used regular font to denote such comments.

2. Linguistic comments: exploring the specific use of language by the participants such as words used to describe experiences, pauses, inflections, intonations.
   - These comments were indicated in *italics*.

3. Conceptual comments: engaging at a more interpretative level, “each interesting feature of a participant’s account may prompt further questions” (p. 88).
   - The researcher *underlined* these comments.

As a starting point for this step, this researcher went through the transcript of the first interview conducted, PC 1, and developed a system for reviewing the transcript and completing the initial noting. A table was generated with three columns: the left hand column provided space for the original transcript with linguistic comments added in italics, the centre column included the descriptive comments or significant statements related to segments of the transcript which
were noted in regular font, and the right hand column provided space for conceptual comments underlined, in addition to notes made by this researcher. In this column, this researcher used an asterisk (*) to indicate specific comments that represented potential emergent themes. A segment of initial noting for this transcript has been included in Table 6 below.

<table>
<thead>
<tr>
<th>Table 7. Semantic Analysis (Smith et al., 2009)</th>
<th>Family: 1; Patient: PC 1</th>
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<tr>
<td><strong>Original Transcript</strong></td>
<td><strong>Descriptive Comments</strong></td>
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<td><strong>Linguistic Comments</strong></td>
<td>Relating cancer story –</td>
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<td>long story with reality of</td>
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<td>cancer spreading several</td>
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<tr>
<td>P: (Pause here before relating the details) -</td>
<td>Relating cancer story –</td>
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<tr>
<td>I had radiation to start, and then I had</td>
<td>long story with reality of</td>
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<tr>
<td>radical surgery to take out a lot of</td>
<td>cancer spreading several</td>
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<td>abdominal organs, because they</td>
<td>times</td>
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<td>thought they could cure me</td>
<td>They thought they could</td>
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<tr>
<td>pause – (voice trailed off here became</td>
<td>cure me</td>
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<td>fatigued in talking). And I didn’t have any</td>
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<td>mass diagnosed polyp for two years. They</td>
<td></td>
</tr>
<tr>
<td>were very reassured there would be no</td>
<td></td>
</tr>
<tr>
<td>mets. (Hesitated) But (pause) then at two</td>
<td></td>
</tr>
<tr>
<td>and a half years, mets in my lung were</td>
<td></td>
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<tr>
<td>diagnosed, and so I started chemo, lots and</td>
<td></td>
</tr>
<tr>
<td>lots (stressed) of different kinds of</td>
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</tr>
<tr>
<td>chemo, one after another. And then in</td>
<td></td>
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<tr>
<td>March, a year ago, (sigh and pause) it</td>
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<tr>
<td>was diagnosed in my pancreas and then liver,</td>
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<tr>
<td>so it’s spreading (said with raised tone of</td>
<td></td>
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<tr>
<td>voice). And I’m still on chemo, a clinical</td>
<td></td>
</tr>
<tr>
<td>trial.</td>
<td></td>
</tr>
<tr>
<td>I: You’ve had a lot to deal with. Do you</td>
<td></td>
</tr>
<tr>
<td>remember what you thought and what you felt</td>
<td></td>
</tr>
<tr>
<td>at that point in time?</td>
<td></td>
</tr>
<tr>
<td>P: (pause – reflecting) I think I</td>
<td></td>
</tr>
<tr>
<td>thought I was dying. I think as soon as I</td>
<td></td>
</tr>
<tr>
<td>found more cancer I thought I was dying. I</td>
<td></td>
</tr>
<tr>
<td>felt like the end of my life was drawing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I thought I was dying.</td>
</tr>
<tr>
<td></td>
<td>I felt like the end of my</td>
</tr>
<tr>
<td></td>
<td>life was drawing near.</td>
</tr>
</tbody>
</table>
near. That’s what I felt (*pause*). I’ve had a lot of cancer in my family. I’m a [name of profession], and so I know about cancer. (*pause*) And so I just felt like I was dying (*pause*). I remember walking around thinking this is the end of my life and what it would feel like if I was dead (*inflection – out of breath*).

Lot of cancer in my family I’m a [name of profession], and so I know about cancer

Remember walking around thinking this is the end of my life and what it would feel like if I was dead.

Fits with uncertainty in illness and anticipatory grief from chapter 2

Again clinical aspect

Unfathomable – thinking about what death would be like; pausing here, appears to be taking time to reflect. But also fatigued

Descriptive comments, significant statements, and conceptual comments of this transcript were read and re-read to further the understanding of this mother’s lived experience, in turn facilitating the analysis and interpretation. This process led to a compilation of meaning units, “parts of the data that even if standing out of the context, would communicate sufficient information to provide a piece of meaning to the reader” (Elliott & Timulak, 2005, p. 153).

Although the steps in IPA involve the completion Steps 1 to 4 with the first transcript and a repetition of these steps with the remaining transcripts in Step 5, Smith et al. (2009) stated, “the analysis is not prescriptive and the analyst is encouraged to explore and innovate in terms of organizing the analysis” (p. 80). That being said, this researcher felt it important to work through the initial noting with each transcript before moving to Step 3. As each audio file had been reviewed, and transcripts read, participants’ stories were vivid in this researcher’s mind. While completing all the initial noting, this researcher ensured that each transcript was treated “on its own terms, to do justice to its own individuality” (Smith et al., 2009, p. 100).

Once the Semantic Analysis was completed for each transcript, meaning units for each were compiled in a word document, examples of which are included in Table 8 on the following page. These were also read and re-read while this researcher went back to the transcripts for
clarification, moving between the whole and the parts, reflective of the hermeneutic circle. This, again, strengthened this researcher’s engagement with the intimate details of each participant’s story. Moreover, this researcher’s ability to attend to detail and engage in an extended immersion with the participants’ stories facilitated increased understanding of the ways the participants thought, felt and discussed the phenomenon. This represented a pivotal process in the analysis and interpretation for this researcher as threads began to pull together.

**Step Three - Developing Emergent Themes**

Looking for emergent themes, or “mapping the interrelationships, connections and patterns between exploratory notes, paying attention to convergence and divergence” (Smith et al., 2009, p. 91) represented the focus of this step. The authors defined themes as “phrases which speak to the psychological essence” of participants’ lived experience, and “reflect a synergistic process of description and interpretation” (p. 92). Emergent themes reflecting the psychological essence began to appear as this researcher worked through the initial noting, and compiled meaning units.

Moving deeper into the analysis and interpretation, Step Three led to “a moving away from working directly with the transcripts to working with the initial notes to develop emergent themes” (Cassidy, Reynolds, Naylor, and De Souza, 2011, p. 269). Moreover, Cassidy et al. noted, “a certain amount of pruning will occur at this stage; the researcher works to maintain the depth and complexity by focussing on the most important and interesting data whilst reducing the volume” (2011, p. 269). Through this step, threads of participants’ stories that were similar in essence became apparent. Interestingly, this researcher noticed that as similarities became apparent, the individuality of each story appeared to become more evident. Dahlberg and Drew (1997) discussed the sameness/uniqueness paradox of phenomenological research, noting,
It is in the ‘parts’ phase of data analysis that the paradox of sameness/uniqueness becomes apparent. The patterns that emerge in phenomenological analysis are in themselves paradoxical. Patterns of the lived world are at once consensual, portraying a commonly shared understanding that makes it possible for productive and meaningful coexistence with others, and simultaneously indicative of the uniqueness of the individuals to whom they refer. (p. 313)

This paradox was fitting with this researcher’s experience in this step of the analysis and interpretation, while making sense of the patterns and connections in the data and emerging themes. For example, although all parents living with cancer knew they would one day die of their cancer, what this represented for each participant, particularly with respect to the meaning and subjectivity, was very different as discussed in the respective theme, Making Meaning: Something that makes no sense. Table 8 represents the development of emergent themes for parents living with cancer.

<table>
<thead>
<tr>
<th>Meaning Units - Statements from Participants’ Interviews and Conceptual Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>PC 1</td>
</tr>
<tr>
<td>PC 3</td>
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<td>PC 2</td>
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<td>PC 4</td>
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<td>PC 5</td>
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<td>PC 6</td>
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<td>PC 7</td>
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<tr>
<td>PC 8</td>
</tr>
<tr>
<td>PC 9</td>
</tr>
<tr>
<td>PC 1</td>
</tr>
</tbody>
</table>
Emergent Themes

- Long journey living in the world of advanced cancer (revolving door with no return)
- Cancer is like a whole crazy wide spectrum of illnesses
- Overwhelming shock of diagnosis (back pain, gall bladder)
- I don’t want to die young
- Mind-boggling, scary, worried, guilt, … what now
- My life is over – this is the end, “I’m done”
- Everything snowballed – I didn’t have time to breathe, World came crashing in
- Constantly felt like going through this revolving door

Step Four - Searching for Connections across Emergent Themes

The emergent themes and connections between emergent themes surfaced. They were woven into themes, “true to all of the most interesting and important aspects of the participant’s accounts.” Smith et al., (2009) proposed the following to enable connections across themes:

1) Abstraction: “a basic form of identifying patterns between emergent themes and developing a sense of ‘super-ordinate’ themes” (p. 96).
2) Subsumption: “an emergent theme itself acquires a super-ordinate status as it helps bring together a series of related themes” (p. 97).
3) Polarization: “examining the texts for oppositional relationships between emergent themes” (p. 97), in essence looking for differences
4) Contextualization: connections between emergent themes, contextual or narrative elements within an analysis – attending to temporal, cultural and narrative themes

Table 9 on the following page provides an illustration of the development of some themes from emergent themes.

<table>
<thead>
<tr>
<th>Abstraction</th>
<th>Over-arching Theme: Thrown into the scary, mind boggling, crazy, wide spectrum, world of advanced cancer with no return</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subsumption</td>
<td>Living Life as Best as We Can</td>
</tr>
<tr>
<td>Polarization</td>
<td>Positives: Good can come from this</td>
</tr>
</tbody>
</table>
| Contextualization | What’s out there to help us cope?  
Theme divided into sub-themes guided by participants’ stories:  
- Supports for Patients  
- Supports for Well Parents/Caregivers  
- Supports for Children - Who can help me? |
Step Five – Moving to the Next Case

As indicated in the discussion of Step Two, this researcher felt it was more appropriate and succinct to work through Steps 1 – 4 for all fifteen transcripts. The analysis and interpretation, therefore, moved to Step Six in the IPA.

Step Six - Looking for Patterns across Cases

In this final step, the analysis and interpretation evolved and deepened as this researcher looked for connections between themes and transcripts. Although this step in IPA is usually outlined in a table, this researcher felt it was more fitting to configure a map of the themes to represent the analysis and interpretation, as presented on the following page. Linking this map of themes to a tapestry, the threads of participants’ stories have been represented through three colours: the parents’ perspectives are highlighted in green; the parents’ and children’s perspectives are highlighted in red, and the children’s perspectives are highlighted in purple. As the overarching theme originated from all three perspectives, it is depicted with the three colours. The research questions (as indicated on page 16) associated with each theme have been included.

Additionally, as this researcher reflected on the hermeneutic circle, the depth and breadth of this process brought a richness and clarity to the understanding. The process of going from parts to whole within a transcript and across the transcripts facilitated this researcher’s ability to focus on the subjectivity of the participants and their truths or essence of their realities, reflective of the fidelity of interpretation as proposed by Gadamer (1976). Step Six enabled a closing of the circle and a returning to the “whole”. The “whole” gained new meaning, in addition to an enriched perspective, understanding and interpretation of the phenomenon. Finally, Chapter Six, the final chapter of this dissertation, provides further discussion of the analysis and interpretation.
Over-arching Theme
Thrown into the scary, mind boggling, crazy, wide spectrum world of advanced cancer with no return
RQ 1, 2, & 3

Living Life as Best as We Can
RQ 1
- Living with advanced cancer
  - I’m still here doing whatever I can to live a bit longer

Making Meaning
Something that makes no sense
RQ 1
- Chronic Caregiving
  - It’s wearing me down
- Searching for WHY
  - A question that doesn’t have an answer
- Hope and Uncertainty
  - How much longer do we have?

A Difficult Balancing Act
Mixing parenting with advanced cancer
RQ 1 & RQ 2
- Difficult conversations
  - Telling our children what we should never have to tell them
  RQ 1 & RQ 2

Distress And Worry
RQ 1 & RQ 2
- Parents and Children

We’re doing as okay as we can
RQ 1 & RQ 2
- Children’s perspective

What’s out there to help us cope?
RQ 3
- Supports for parents living with cancer, well parents, and children

Chronic Caregiving
It’s wearing me down

Positives
Good can come from this
RQ 1

Distress And Worry
RQ 1 & RQ 2

Over-arching Theme
Thrown into the scary, mind boggling, crazy, wide spectrum world of advanced cancer with no return
RQ 1, 2, & 3

Parents’ Perspectives
Parents’ and Children’s Perspective
And Parents’ Perspectives of their Children’s Experiences
Children’s Perspective

Final Thoughts
Advice from Us
RQ 1, 2, & 3

Themes are indicated in bold font.
Sub-themes are indicated in plain font.

Figure 6. Map of Themes
Discussion of Themes to Further the Analysis and Interpretation

The next section of this chapter will present an in-depth description of the themes presented in the map of the themes, furthering the analysis and interpretation. Exemplars of participants’ stories depicting the essence of their lived experience were selected to illuminate the themes, and will be interwoven with interpretation to further the understanding of the phenomenon of children and parents living with the uncertainty of cancer.

**Over-arching Theme: Thrown into the scary, mind boggling, crazy, wide spectrum, world of advanced cancer with no return** (Research Questions 1, 2 and 3)

As this researcher was reviewing the emergent themes for parents living with cancer, well parents, and children, she made note of specific words used by the participants when discussing cancer. When configuring the themes, this researcher wrote the words used on a page and instantly felt that by putting the words together, they captured an over-arching theme. Threads of this over-arching theme were repeatedly apparent to this researcher during the reading and re-reading of the transcripts, the initial noting and compilation of meaning units. With regard to the children, their knowledge of the world of cancer began when they were told of their parent’s cancer, and therefore, the aspect of telling children will be discussed later in this chapter.

Common to the narratives of all parents was the fact that they had no idea or suspicion that the health concern they sought advice for would lead to a diagnosis of advanced cancer, as indicated in the following, “*I went to the doctor for back pain and came away with advanced metastatic cancer*” (PC 2), “… pancreatic cancer. It wasn’t expected, that’s for sure…because I feel fine I… I didn’t have any symptoms…other than heartburn from a gall stone” (PC 7), “*She noticed a lump, and, she thought it was some form of mastitis or — something was going on, which is typical, um, for breastfeeding mom. … then it was stage 4 metastatic breast cancer*” (WP 4).
For all parents interviewed, the experience of hearing the words *it is advanced cancer* was profound and personal. Each parent responded in unique, but similar, ways from overwhelming shock, to a deep sadness of what might have been, and for some, an adjustment to the diagnosis with time. The life altering event of having their worlds ‘turned upside down’ while not having a manual or road map was echoed by the parents. This was particularly true for the young couple as parenting their small children was shaped by advanced cancer, and pending death.

Following a discussion of the circuitous route to diagnosis, parents living with cancer and well parents provided clear narratives of treatments, recurrences, and any relevant details, depicting the scary, mind boggling, crazy, wide spectrum, world of advanced cancer. For five parents, their worlds of advanced cancer spanned several years (diagnosed 2006 to 2012). Their cancers ebbed and flowed, with periods of calm between treatments, followed by a downward movement from one plateau to another as their cancers progressed, and treatment options narrowed. This was aptly described by one husband following treatment his wife received, “*We were in this position for 1 ½ years – not knowing when the shoe is going to drop*” (WP 4). Unfortunately the other shoe did drop, and his wife was diagnosed with metastases to the brain.

For two parents diagnosed in 2015 and 2016, the world of advanced cancer had become a recent reality. As a result, their narratives related to the details of cancer were less complex, but just as mind boggling. Pending surgery, one parent said, “*I thought that maybe if they opened me up there would be no cancer – but then I hear it’s the worst stage of it so it was - well- my life went completely dark*” (PC 6). Regardless of the time frame, all narratives were filled with vivid description. Following his interview, one well parent related that the demands of living with advanced cancer were more than a full time job and it was “*relentless, overwhelming and exhausting*” (WP 1). Another well parent sighed and said he “*had no time to breathe*” (WP 6).
**Living Life as Best as We Can** (Research Question 1)

While this researcher was working through the interviews and the plethora of data, several emergent themes clustered together around topics associated with the parents living with cancer, while others were associated with the well parents. In configuring the map of themes, a common thread was woven through each story; living life as best as they could. This researcher, therefore, felt that the thread was strong enough to represent a theme on its own, and through “subsumption” this emergent theme “acquired a super-ordinate status” as it brought “together a series of related themes” (Smith et al., 2009, p. 97). Two themes were brought together; 1) I’m still here - Living with advanced cancer; and 2) Chronic Caregiving - It’s wearing me down.

**I’m still here - Living with advanced cancer.** Very evident in the narratives for the ill parents was an ardent need to do whatever they could to live normally for as long as possible, “sustaining ‘double awareness’ of the possibilities of life while also facing the end … the challenge for those who are both living and dying” (Rodin, 2013, p. 926). They needed their children to see them as their normal parents, and to have minimal disruption to their lives, as depicted in the following, “They [the children] understood what it was, but then from their perspective, things were normal. ... I looked normal, acted normal” (PC 3), “It’s important for me to keep the family as routine as possible, I don’t want too much to change.” (PC 7), “I wanted their lives to remain as normal as possible. ... I wanted to look after them. And, you know, I was mad, I was sick too, and it wasn’t fair. But we really tried to maintain a normal life” (PC 1). The parents’ thoughts were consistent with the research. Semple and McCance (2010) outlined three concerns for parents living with terminal illness: parental competence (being a good parent); communication with children (how to talk about illness); and maintaining routines at home (the need to maintain normalcy).
This ardent need for normalcy in the face of uncertainty was also important for the ill parents, personally. Following a recurrence, one parent felt it important to take “new baby steps in learning how to live my life – manage life differently. So I just have to keep persevering” (PC 5). She added a comment about her husband’s reaction to managing life differently, “My husband doesn’t fully understand. He talks about it sometimes ... I want the old [wife’s name] back. My response - She’ll never be back 100% - I’m different” (PC 5). Each parent voiced the importance of being as independent as possible. This moved from periods of dependence during treatment to periods of independence, albeit it diminishing with progression of their cancer. For each parent, being dependent on their partners was a sign of how much the cancer had taken from them. One mother voiced her frustration at being dependent not only on her partner, but also on her teenage son, whom she felt should be out experiencing his own life.

**Treatment - Doing whatever we can to live a bit longer.** In doing whatever they could to live life as long as possible, there was an expansive amount of commentary related to treatment and side effects, all of which were tolerable if it meant living for one more day. Although not a full theme, this researcher felt the data encompassed a sub-theme. The nature of treatment ranged from radiation, chemotherapy, hormone therapy, and surgery, with extensive side effects, as indicated in the following, “I’ve had the kitchen sink – treatment, radiation therapy, clinical trial, hormone therapy and chemo, all dependent on rising and falling PSA level” (PC 3), “I’m sort of living my life between approved drugs in Canada and non-approved drugs, experimental stuff. And some of these are ridiculously expensive!! ... They don’t cure you, but they make you live pretty... you have a good quality of life for a longer time” (PC 2), “The side effects of treatment were really severe, lot of difficulties – I was just one of those patients who has problems” (PC 5).
Despite extensive treatment and unpleasant side effects, they related they would endure whatever they had to, if it meant they could remain alive for their children and partners. Comments by three mothers depict this. When discussing the metastases of cancer to her pancreas and liver, knowing this would limit her life, one mother stated,

*I made them know that I was a fighter. You don’t give up in life. You don’t just think, oh, it’s going to be bad. You say, “No, I’m going to make it good, and you can control your body. Mom is going to fight.”* I wanted them to be strong so I had to be strong. (PC 1)

The youngest mother stated that all she endured resulted in her being able to do what she felt was “the most important thing … being able to spend quality time with my family” (PC 4). Her comments about living as long as possible for important milestones in her children’s lives highlight the meaning of this thread for the parents who were dying, which this researcher was reflective of “cram parenting” (Bell, & Ristovski-Slijepcevic, 2011).

The mother of the nine year old daughter had to cope with severe side effects of treatment in an effort to stall the progression of her cancer, and be there for her daughter,

*I had severe side effects for this trial, and like my hands swell up … my feet really took a beating. They’re still peeling, I had like problems walking. Sometimes I could barely make it to school with her in the morning [the school is two blocks away] …like I had rocks stuck in my feet … The medical team kept saying to me, ‘You know, you really persevered, really pushed yourself to the limit’ I was trying to survive for my daughter, basically and to give her somewhat the normal life.* (PC 5)

**Hair Loss - Put a scarlet “C” on my forehead.** Hair loss stood out in the interviews as an unwelcome side effect of doing whatever it took to live as long as possible. It is interesting to note that the perspective on this was different for the parents with cancer and the well parents. Children’s comments will be included in a later theme. For the ill parents, both male and female, it was difficult to cope with, and a sign of how unwell they were, as typified in the following:

*The very first treatment I had made me lose my hair, and that was a big deal because I had gorgeous hair, and it’s never grown back the same. … I miss my hair.* (PC 1).
I used to have my red hair highlights with my red/burgundy hair. It was part of my appearance. So I felt that, um, especially the wig, it’s like a Scarlett “C” on my forehead, like to show that you’re going through cancer, right. My hair has been very devastating along with my weight gain. (PC 6)

I couldn’t understand why I was upset about it, I’m not a high maintenance person, My psychiatrist who I am seeing talked with me about it – clarified – losing hair on chemo – coming out of the closet – makes cancer real – being exposed to the world as having cancer. (PC 4)

The mother who was recently diagnosed with pancreatic cancer was just starting to lose her hair at the time of the interview, however, she echoed the sentiments of the other parents,

*Shedding scares me. My hair is a symbol of cancer. Hair loss is making it very real – a visual symbol. Because I had no symptoms so the hair loss is what I feel is making me look the part. I’m sad that it’s shedding.* (PC 7)

Interestingly, the well parents did not see it in the same light, indicating it was not an issue for them. One parent related a comment made by his wife, “The other day, just out of the blue, she was looking at me for a second while I was reading, and she said, ‘You know, you look quite handsome without hair.’” He commented on his children’s reaction, “They make light of it - joke about it. You should wear a do-rag.” Having lost his hair twice from treatment, this father did not share their opinion, “I don’t like it. I’m not used to it. I think I look better with my normal hair than I do without any hair” (PC 3). Finally one mother described a significant family moment related to her hair loss,

*When it all fell out, it just leaves little scraggly bits, so my daughter actually shaved my head. I remember I was in the bathroom and my daughter was shaving my head to get all the little scraggly bits off, ’cause I was going to start wearing a wig. And she shaved my head while in the same bathroom my son shaved for the first time. It’s kind of an intimate experience.* (PC 1)

**Chronic caregiving - It’s wearing me down.** Caregiving was an extensive focus of the world of advanced cancer for the well parents. The double role indicated in the literature was the day to day reality for the well parents, particularly for two parents who had been caregiving the longest. As death loomed, their circumstances reflected the research; caregiver burden increases
as the partner’s status declines (Grunfeld et al., 2004). Supporting a partner living with advanced
cancer while parenting triplets would seem unfathomable, however this parent had found a way
to balance roles in addition to working. Despite a very demanding job, he limited his travel and
daily hours to be there for his wife and children. The chronicity of his life circumstance was
evident in the comments he made about his roles, two of which were particularly significant,

People have told me take care of yourself and make sure you don’t get too run down, whether it’s eating or exercise or drinking. You’re in quite a very vulnerable spot, I can see that.

Well, no one... not no one, relatively few people ask how I’m doing with this whole thing. Ninety-five percent of people ask how she’s doing, which is great. But not that many people have the insight to know what the impact on you is.

Since 2012, life for the youngest father had been defined by cancer. Being the primary
parent for both children since their daughter was four months of age, while their mother’s health
became more complicated, had put considerable strain on him. He used the term “guilt fatigue”,
which this researcher felt was significant in capturing the nature of this theme,

I’m the predominant caregiver for them and being the reliable one. ... Having caregiver fatigue looking after them and the kids you feel almost like a guilt fatigue in some ways. ... You’re tired of being pitied in some way and it’s not good to feel that way— long term, right ... It’s chronic right – it is very hard when it’s chronic. (WP 4)

Finally, while bearing witness to the well parents’ narrative accounts of their double lives
defined by cancer, this researcher reflected on what Aamotsmo and Bugge, (2014) referred to as
“balancing artistry” and “new roles without a script” (p. 323).

Making Meaning - Something That Makes No Sense (Research Question 1)

Trying to make sense of something that may not make any sense was apparent for the parents living with cancer. Why did this happen, why did cancer return, what went wrong, and the conflict of living with hope and death in an uncertain world were threads woven through their narrative accounts. For the well parents, there appeared to be a difference in this regard. For this
theme of making meaning, emergent themes clustered around two sub-themes that were especially interesting.

**Searching for WHY - A question that doesn’t have an answer.** In reflecting the participants’ narratives, there were two different depths of thought about this question with no answer. Sitting with each parent living with cancer, this researcher was struck by the frankness in discussing their search for why were their worlds turned upside down at a time when they should be enjoying their lives, as professionals, partners and parents. One parent, diagnosed several years ago, thought about it a lot at that time and remembers her thoughts and self-blame,

*Thinking about why I got it, I think a lot. I think I’ve thought a lot about it. I got it because I’ve always been a very uptight person, you know, very high-strung, very busy. I always thought I got cancer because I rushed around so much and was so intense. But I think I often blamed myself and my personality for getting it, that there was some meaning or some reason.* (PC 1)

One parent focused on always doing the right thing, and getting “slammed” with cancer anyway,

*Why this happened – absolutely. Wonder why – when you always try to go above and beyond helping people or being nice and never speaking ill of anyone or trying to go out of your way to be a good person. And you get slammed with this. Why do you deserve this? Whereas other people you see are not as nice – malicious – and they don’t get this. It’s a question that doesn’t have an answer.* (PC 6)

Recently diagnosed, one parent indicated that this was perpetually something she thought about, and she stated that she had a good idea of why,

*Our marriage wasn’t 100% for the last few years so I believe a lot of it is just that I thought I was dealing with it ok but I guess it is the chronic stress of our marriage not 100%, And now it’s better. Like, I mean, since diagnosis, I gave him an out and he chose not to and he said, “No, I’m your husband and you’re my wife and I love you,” and yeah, and so, he’s been great - He’s been… it’s like I got my old husband back.* (PC 7)

With regard to the well parents’ thoughts about why their partners were diagnosed, this researcher made an interesting observation. Although each provided commentary regarding their partners’ thoughts, the well parents provided little commentary on their own thoughts, merely
stating, “It was really, really bad luck”, or “it was random, or genetics.” It was interesting that the ill parents were very focused on formulating some answers, while their partners were not.

**Hope and uncertainty - How much longer do we have?** A facet of all parents’ interviews was the capacity to hope with death looming in a very uncertain world, “an everyday life where uncertainty is ever present like a shadow” (Arkitel, 2015, p. 8). Initially, all parents were hopeful of an incorrect diagnosis, the medical team got it wrong, and it’s not cancer. As diagnoses were confirmed, hope shifted to a cure. This was true for the mother diagnosed with abdominal sarcoma,

*But I felt very confident - hopeful that I would fight it. I always believed in a miracle. I always believed that I was stronger than the average person, and I wouldn’t be a statistic. I – I was going to be the one to get cured.* (PC 1)

However, in time the hope for a cure was also dashed, magnifying uncertainty. Hope rapidly became a hope of living longer, beating the odds, a new treatment being developed, minimal pain, spending more time with partners, and watching their children grow up (milestones). During the course of their cancer, hope and uncertainty were ever present. As individuals felt more hopeful, uncertainty waned, however any change in circumstance resulted in increased uncertainty while hope waned, indicative of Mishel’s Uncertainty in Illness Theory (1988). This researcher was drawn to the following comments by parents which depicted the magnitude of uncertainty in their worlds, “The hardest part - fear of the unknown, that’s scary” (PC 7), “I didn’t know what to think. When you have a diagnosis like that, you don’t know if you’re going to live, not … it was devastating” (PC 6), “We don’t know how long I can hang on to this, you know? It’s to figure out the future. How do we do things in the future” (PC 2), “Having young kids, I think, just made it that much worse. I didn't know what to expect” (PC 3), “We’ve been forced to ask questions that we may not have asked until we were much older in our
A Difficult Balancing Act - Mixing Parenting with Advanced Cancer (Research Questions 1 and 2)

Parenting while living with terminal cancer, or as the well parent represented an integral part of this study. Comments stated by parents in the initial discussion of the study with this researcher reflect the difficulties, “Cancer makes parenting frustrating” (PC 2), “Add cancer to the mix and it can become a very difficult balancing act with lots of moving parts” (WP 4). The parents were aware of the effects of cancer on their families and the daily challenges related to being a parent, especially that of their efficacy, as indicated in the reviewed literature (Aamotsmo & Bugge, 2014; Rauch & Muriel, 2004). The parents were asked about their role as parent prior to, and following cancer disrupting their family life. Each parent stated he/she enjoyed being a parent, and spoke with a sense of pride about their parenting role, “I loved parenting before cancer,” “I loved everything about fatherhood,” “I always had a good relationship with both children.”

With regard to the effect of cancer on parenting, the thoughts of the participants were revealing, “I’m much calmer, I think. So I’m much more approachable” (PC 1), “I’m a lot more patient. As a parent, I like this new me better” (PC 5), “I’m a lot more delicate with her and I like this new me better. So it’s actually helped us get even closer” (PC 7). As anticipated death shaped her parenting, the youngest mother said, “I’m more lenient – don’t want them to remember me as the bad parent. Discipline is an issue – I’m more lenient because not wanting to fight with them. ... It would be nice to just be a parent without the background of knowing you are going to die and what their memory is of you” (PC 4).
An additional aspect of parenting pertained to emotional security for their children before and during cancer, data reflective of Research Question 2. Each parent’s narratives clearly depicted that prior to the disruption of cancer, he/she represented a source of emotional security, or an attachment figure, for their children, particularly if the children were emotionally upset. It was apparent that the emotional security post diagnosis and during treatment was very dependent on all parents’ emotional availability and attunement. For the ill parents, this was affected by the level of compromise experienced by those “living with a life-threatening illness’ and those “actively dying.” Two ill parents (PC 5 and PC 7) reported what this researcher felt was a strengthening in their attunement and ability to provide emotional security to their children as they coped with their parents’ cancer, reflective of emotional holding and containing. The emotional availability of other parents waned considerably as seen with the mothers who were the most compromised (PC 1 and PC 4). For the mother who was diagnosed in 2007, her partner (well parent’s perspective) related that he could see the struggles her cancer had on her ability to parent, especially emotionally. This was due to her declining health, but also the overwhelming optimism she needed to maintain. The father said this resulted in the children going to him for emotional support around what they knew, their mother was dying. He related a comment made by his daughter, “Well, she’s telling me she’s feeling really good but I think she’s lying to me.” From this father’s perspective, his daughter’s comments may stem from mixed messages she perceived and a felt sense that her mother was dying, indicative of conscious and nonconscious emotional currents in the intersubjective space (Hughes, 2007; Siegel, 2007). The father added that he was aware of the importance of supporting his children emotionally, in essence strengthening the attachment, affective attunement, and limbic resonance with his children (Schore & Schore, 2008).
I’m trying to be... so I go to a psychiatrist who’s helping me to be as positive with them as possible, and in touch with them in terms of relationships, so that regardless of what happens, I can be close to them and support them. So this is what I’m trying to do. (WP 1)

With regard to the mother dying of advanced breast cancer, the effects of her cancer and treatment, and in particular the metastases to her brain and whole brain radiation, not only compromised her physical and cognitive abilities, but also her parenting. She related that she had been unable to pick up and hold her children independently, especially when they were upset.

Her diminished parenting was voiced in the father’s narratives, “Um, so I would say that some of the themes are through this period of parenting, particularly, chemo, and, um, I think there’s a lot of sadness because you’re alone a lot of the time” (WP 4). Two additional threads which this father focused on were of interest to this researcher. In the first, he reflected on his own mother speaking assuredly with a smile as he remembered the positive role his parents played in his life,

I grew up with 2 amazing parents but if I was raised just by my father, I think I would have been a much different person. So knowing how much my mother meant to me growing up through the years, not just till I’m six years old and four years old scares me.” (WP 4)

The second focused on the strength of his relationship with his four year old daughter and what he perceived to be her comfort in relating to men. This is fitting for this child’s life circumstance as her father had been her primary caregiver and attachment figure since four months of age,

[Daughter’s name] I mean—if anything, is, is, we definitely have a stronger bond and to the point where I’ve noticed, you know, I mean, I, I would, you know, I ended up bottle feeding her, which I didn’t have with [name of son], right? So the closeness with her and I is a little bit different - in a lot of ways. Uh, and that, and that shows through in a lot of ways in her relationship with men because we have another, uh, friend, who is around a lot. And he, uh, he bottle-fed her, and she loves him dearly. But she, she has a thing with men. If she, I almost, you know, would love to see her approach if she could go sit in a woman’s lap or a man’s lap. She would probably go to the man’s lap first. Just because she’s used to men looking after her. It’s very strange. It’s a very it’s—interesting. (WP 4)

In reflecting on Research Question 2, this father’s comments depict the importance that attachment is not determined by gender, but emotional attunement and shared emotional experiences within the intersubjective space.
A final facet of this theme related to parents’ perceptions of the effects of cancer on the children. The narrative accounts of parents’ perceptions of how their children were doing were consistent with the children’s narrative accounts of how felt they were doing. This was due to the parents’ ability to be emotionally available, as previously discussed. Additionally, parents were aware of the importance of communicating with their children about their cancer, effects of treatment, children’s worries, in addition to life in general. Research by Kennedy and Lloyd-Williams (2009b) validated the importance of communication as a critical aspect to positive outcomes for children. Communication related to this study and the existing literature will be a focus of the summary of this dissertation included in the following chapter.

Difficult conversations - Telling our children what we should never have to tell them.

Associated with Research Questions 1 and 2, this researcher felt that the rich commentary related to telling children about the diagnosis of a parent’s cancer and treatment, in addition to supporting the children emotionally, represented a sub-theme. All parents and children spoke about what it was like to say and hear such news, particularly with respect to co-construction of meaning. Parents of five families told the children following confirmation of the diagnosis. For two families, however (Family 1 and Family 5), the parents chose not to tell their children about the first diagnosis. For the mother of the triplets, she felt that it was important for her children not associate her cancer with death as reflected in her comments,

... We never told them it was cancer, because my father had died of cancer, and I felt like they’d go right to death, right to “Mommy’s going to die.” And I just couldn’t have that association, especially because everybody did feel that the tumour was tiny and they caught it early I didn’t want them to associate my diagnosis with death – so we didn’t use the word cancer. We called it a little lump that was going to be taken out. (PC 1)

The mother of the nine year old did not tell her daughter initially, as she wanted to protect her and ensure her life was as normal as possible. When their cancers returned, both mothers felt it
important to tell their children about their cancer because a shift in treatment meant physical
effects such as hair loss. As a result the co-construction of meaning related to cancer for these
two families (Family 1 and Family 5) began well after the initial diagnosis.

When parents did tell their children, they related that they chose to do so as a family
conversation in which the parents were as open with their children as they could be, respective of
their children’s ability to understand. From the parents’ accounts, the conversations appeared to
fit with the description of Measured Telling proposed by Sheehan, et al. (2014). The authors
indicated that such conversations were “thoughtfully considered”, and “parents carefully and
rationally determined the nature, the amount, and the timing of disclosures” (p. 515).
Additionally, from the parents’ perspectives, these conversations provided effective support for
the children in their construction of meaning. For the youngest family, the mother related they
used the word cancer almost immediately and that they were very open in the house. She stated,
“[son’s name] knew the word cancer when he was 2. ... They’ve been living with cancer their
whole lives. So it’s all kind of normal. They’re not afraid of cancer the same way as an older kid
would be.” Additionally, most of the parents stated that they assured their children they were not
hiding information and they would keep them informed as needed, “I tried to be as honest as I
could. I promised them there’s no secrets. I promised them as we go along anything I find out, I
will tell them” (PC 7).

As death was becoming a reality for four parents, it is important to include the ways
parents discussed this with their children as there were two different approaches. The youngest
mother related the discussion which she and her husband had with their children stating,

It took us a bit to talk about “Mommy’s going to die”. We weren't sure about how, how to
actually translate cancer into, into “die.” Especially because at, at his age, and at [daughter’s
name]’s age, they don't really understand what that means completely. ... So we talked first to
them [Dr. Jay], and they, they said, um, you just, well, you just need to be honest and talk about
what, what death means, so we... we, ah, just sat down and talked to them about it. And it seemed like [daughter’s name] wasn't listening, but later on she asked some questions, so she was, was listening. We just said “Mommy's going to probably die from” - or “is going to die from - from cancer. Um, we don't know when.” And, and, and, tried to explain what death meant. (PC 4)

The father’s narrative accounts were very similar to the mother’s. Additional comments made reflect the level of understanding of the children, and their construction of meaning,

And sometimes stuff comes out slowly, you know. Ah, for him, it’s kind of like a slow leak, right? Every now and then, he’s thinking about things, and he’ll ask. And, um, you know, he’ll notice things like, uh, if—and [daughter’s name] as well. You know, if they see something on TV, and there’s just a dad and kids, they’ll say, “What happened to their mom? Did their mom die of cancer?” And they—she might just not be in the scene—so they’re trying to make that connection. Um, so they’re, I think they’re processing it, right? Um, and I think they will. And I think they’re very resilient. Kids are resilient. (WP 4)

Both fathers with advanced prostate cancer said they told their children of the change in their cancer, commenting that it was important for their children know that they would die,

We don’t know how long I can hang on to this, you know? It’s to figure out the future. How do we do things in the future? (PC 2)

We thought we had to tell the kids. We did it [at] Christmas time ... Since then, it’s interesting – my son's been more demonstrative than my daughter's been. I think she's the one that's kept it inside more, which may be not a good thing. He's been noticeably more, what's the right word, sweet. (PC 3)

For the parents of the triplets, there was a difference in their approach as the mother’s impending death was not talked about openly with the children. The mother said that six months prior when her status changed, she and her husband had a conversation with their children,

But at Christmastime I started to get sick and feel sick. I felt like I didn’t want an elephant in the room. I wanted to be very open, and so I just... we had a very open conversation about things were a little bit worse, things were bad. They were not great. I was continuing to fight!! They were continuing to offer treatment, but they had to know that time is precious and we need to be together as much as possible and not fight and not be petty, but to support each other. It was a very frank conversation with them about six months ago. (PC 1)

Although this mother felt the discussion was important to have with her children, her comments may reflect Skirted telling: Beating around the bush, as proposed by Sheehan, et al. (2014, p. 515). She “did not hide the truth or lie” to her children, but she “avoided revealing information
straight out.” Since that time, she stated that she had not talked openly with them about dying.

The father experienced frustration about the inability to talk about her pending death with their children. He related it was “obvious that she is not doing well, and not going to survive and the children are aware of it,” but his wife “still remained positive and optimistic.” He added,

She [daughter] just left on Sunday this past weekend and she’s actually said to me – we’re a couple of moments in the car – she said, “Do you think Mommy’s going to die this summer?” Which was the first time she openly mentioned that. I told her the truth, which is I’m not sure. You know, I try to treat her more and more as an adult. She’s [wife/mother] feeling sicker and sicker. I’ll say to her [daughter], “Listen, I’m always going to tell you the truth. I’ll tell you how I’m feeling and I’ll tell you what my concerns are.” That seemed to go fine. (WP 1)

In summary, the parents who participated in the study (well parents and parents living with cancer) were very aware of the difficult balancing act created by the effects of advanced cancer and treatment on themselves, their ability to parent, and on their children. This was evident from the parents’ perspectives but also from the parents’ perspectives of their children’s experiences. Whether recently diagnosed or nearing the end of life or caregiving, each parent clearly gave voice to their need to be emotionally responsive and to support their child/children in creating meaning of the situation. The parents were also aware of the changes to their attachment relationships with their child/children (perceived or actual) and ardently tried to support their child/children in this regard. This researcher was very interested in the synchronicity of the parents’ perspectives with their children’s perspectives, discussed in the following theme.

We’re Doing as Okay as We Can - Children’s Perspective (Research Questions 1 and 2)

The multiple, complex and emotionally laden challenges that stem from living with a parent diagnosed with advanced cancer can overwhelm children. The children interviewed were affected by their parents’ cancer, however, their commentary reflected an aspect of doing as well as they could. This was due to their resilience, but also because of their parents’ attention to their needs, as discussed. Comments from the children clustered into sub-themes. Children related
their thoughts and feelings about their parents’ cancer, how they were told, reactions to their parents’ treatment and hair loss, and their need to be positive and strong. They also talked about who was helpful and what they felt they needed, which will be discussed in the final theme, What’s Out There to Help Us Cope? Finally, this researcher was humbled by the children’s ability to communicate their thoughts and feelings so articulately that an adult, unknown to them, could understand what they wanted to convey.

**Our thoughts and feelings about our parents’ cancer.** With regard to their construction of meaning of their parents’ cancer, three of the four children remembered this aspect, however, the youngest child did not. He stated, “I just know because most people told me. She’s going to die soon.... That makes me too sad” (CD 4). Only two years of age when his mother and father told him, he could not remember the original discussion. His comments do, however, reflect the recent discussion of her impending death, which has shaped the family’s construction of meaning. Although unable to remember how she was specifically told, the nine year old recalled her mother talking with her, and feeling “worried, worried about the tests” (CD 5). As their mother’s diagnosis of pancreatic cancer was recent, the daughter related details of the conversation, “My parents sat us down and told us – we cried a lot.” (CD 7a). She elaborated that it was a “surprise!” adding,

> I was overwhelmed and shocked ... I was upset about that for a few days but then she told me that there are lots of people supporting me and there’s lots of people I can talk to and that made me feel better. I was scared because there’s no knowing what could happen. I knew everything was going to be ok.

Despite being shy, her brother voiced his thoughts and feelings, saying “I felt like, well, sad. Because … because she has to be in the hospital”. (CD 7b). His concerns focus on fear of separation from his parents as discussed by Christ (2000). Both children’s comments were consistent with their parents’ comments about their children’s reaction.
**Treatment – the things they did to help.** Each child had a good understanding of their parent’s treatment and the effects, indicative of their parent’s ability to talk with their children and support construction of meaning. Relating that she knew her mother had scars, the nine year old said “it was from surgery” and that she “didn’t like her mom being in hospital.” She added that “She takes medicines. ... She takes them there [in the hospital]” (CD 5). For the eleven year old, witnessing her mother’s chemotherapy “was scary for the first time but I’ve gotten used to it so I’m not as scared. I’m not as bothered by it as before” (CD 7a). Her brother’s opinion about his mother’s chemotherapy was similar, “When she has chemo I don’t get to see her that often” (CD, 7b). The youngest child was equally as clear, however, there was an element of sadness to his comments as he stated, “... but it’s kind of not really helping – she is going to die” (CD 4).

With regard to hair loss, the children had an understanding of why this happened, and spoke about what this meant to them. “Mom has cancer – the cells that are her hair get zapped as well and her hair keeps falling off and off” were the comments of the six year old. He added, “I feel bad – I won’t see her long hair again” (CD 4). The daughter of the mother living with metastatic melanoma smiled and said “It’s still the same colour, it’s very curly now - used to be much straighter” (CD 5). When asked this about his mother’s hair loss, the nine year old said, “She’s going to lose it – it is falling out. It’s kind of like weird. My dad is bald and my mom looks like of like him – they’ll look the same” (CD 7b). His sister related, “It’s thinning – I keep telling myself that it’s just a temporary thing – it’s going to grow back. It does scare me to see her pulling out a lot of hair. But it’s just hair and I know it’ll grow back” (CD 7a).

**Being strong and positive.** An additional sub-theme focused on children’s thoughts about needing to be strong and positive for their parents. As they knew their parents were sad or worried about cancer, trying to make their parents feel better was woven through the discussion.
The research by Kennedy and Lloyd-Williams (2009a) is associated with the narrative comments of the children participating in this doctoral study, particularly with regard to children’s sense of emotional responsibility to support and comfort their parents, in conjunction with the need to be strong. This will be expanded on in the following chapter in reflecting on the research questions of this study. Commenting on his father’s sadness, the six year old said he tried to help his dad when he was sad, “I feel sad for him - I cuddle with him” (CD 4). When the nine year old knew her mother was not feeling well, she stated,

Well, I feel like I need to be strong...so that they should, um, that the... the parent with cancer doesn’t feel so worried and a bit more if they’re scared of all these treatments and medicines and operations, they can probably just feel a bit more brave. (CD 5)

Also stating he had to be strong because he was worried for his father, the nine year old focused on tangible ways to help his father when he was worried, “Yes [he worries about his dad]. Because my mom can’t do anything. I help my dad when he is doing things to help my mom. I set the table, and clear up” (CD 7b).

If her mother was not feeling well, the eleven year old said,

Yes – being strong and positive is what I try to do. Because if you’re just negative and miserable all the time you’re just making things worse. So I think being positive and strong, um, lifts your spirits up and you won’t worry as much. ... I try to make my mother feel better. I am going to make a nice gift for her for Christmas – a book of all inspiring quotes. And I try to make her laugh. (CD 7a)

In summary, the children provided rich discussions of their thoughts and feelings about their parents living with cancer, and their well parents. There were common threads as depicted in the exemplars, in addition to differences, reflective of the sameness/uniqueness paradox. It was clear to this researcher that each child was actively trying to make meaning of the situation. Their meaning flowed from their parents’ responsive communication and emotional availability within the intersubjective space which supported the children’s understanding and emotional security. Some of the children’s commentary focused on what could be seen as perceived
changes to their relationship with their parents (attachment relationships). This was evident in the six year old trying to make sense of his knowledge that his mother was going to die, and the nine year old who did not like his mother going to hospital because he would not see her. Finally, worry about their parents was a clear thread, which will be elaborated on in the following theme.

**Distress and Worry** (Research Question 2)

Living with, and dying from, terminal cancer increases the emotional distress experienced by individuals. The literature indicates that parents’ distress and children’s worry can amplify with change of circumstance, particularly moving from living with terminal cancer, to actively dying. For the children who participated in this research, their worry focused on their parents’ cancer, witnessing the effects of treatment on their parents, their well parents, and emotional security, in addition to the threat of death of their parents. Children’s narrative comments about worry emulated the research (Christ, 2000; Christ, & Christ, 2006; Kennedy & Lloyd-Williams, 2009a; Phillips & Lewis, 2015). The Worry Meter for Children, a non-standardized measure developed by this researcher, provided an informal measure of the level of worry experienced by the children who participated providing further data for Research Question 2. Children were asked to indicate the highest level of worry they have felt since they were told of their parent’s cancer, the lowest level, and what the level was on the day of the interview. Children were then asked if their worry ever grew bigger than the respective number each provided as the highest level. Each child was then asked what he/she did if the worry grew too big. To provide an understanding of distress experienced by the parents, the Distress Rating Scale for Parents was adapted from the Worry Meter.
**Level of distress for parents.** The highest level of distress for all parents was consistent, ranging from 8 to 10+ and was associated with events such as diagnosis, bad news, or impending death becoming a reality. The lowest level ranged from 1 to 5 and was associated with good news and minimal symptoms. Their level at the time of the interviews fluctuated, ranging from 0 to 8. The fluctuations reflected the variability of the ill parent’s status, living with compared to actively dying.

**Levels of worry for children.** With the exception of the youngest participant, each child was able to identify his/her highest level of worry, the lowest level, and the level of worry at the day of the interview. The Worry Meter was adapted for the six year old whose mother was dying. Although he understood the scale, as he was two years of age when his mother was diagnosed, he could not remember that time. He was able, however, to identify the current level of his worry about his mother, which he said was the highest. The highest level of their worry ranged from 6 to 10+, due to shock of learning about the parents’ diagnosis, worrying about treatment, or death of the parent (similar to the parents). There was consistency in the lowest range of worry, 1 to 3, as the children remembered when their parents did well, similar to the parents. There was considerable fluctuation with the current level of worry, 0 to 10+ (as reflected by the parents). The 9 year old whose mother was doing relatively well with treatment for pancreatic cancer felt his worry was 0, while 10+ was indicated by the 6 year old who knew his mother was dying.

When the children were asked if the worry for the parents ever got bigger, they all said yes. With regard to what helped them cope and reduce their worry, the children related they talked to their parents (well or ill), and significant adults which helped contain their worry, sensitive emotional attunement. The emotional security felt by the children was reflected in their
comments, “I talk to my mom and dad. ... I cuddle with them” (CD 4), “I spend more time with my mom” (CD 5), “I talk with my mom ... I have lots of people I can talk to – it won’t last forever” (CD 7a).

Coping with their fluctuating worry could be indicative of Porges’ Polyvagal Theory, as discussed in Chapter Three. Perhaps cues from verbal and non-verbal dyadic communication between parents and children calmed the children’s “physiological states and shifted fight/flight/freeze behaviors to trusting relationships” (2015, p. 4). In that regard, the emotional security felt by children, who participated in this study, which was resultant from the emotional availability of the parents contrasted the literature reviewed indicating parents often discounted their children’s emotional needs, feeling their children were coping. Moreover, the ability of the parents in this study to be emotionally available, supporting their children’s emotional security, is indicative of concepts of attachment, intersubjectivity and neuroscience; being emotionally attuned and responsive to children in uncertain circumstances.

**What’s Out There to Help Us Cope? Supports for Parents Living with Cancer, Well Parents, and Children (Research Question 3)**

During the interviews, all participants were asked about what helped them cope, in addition to what they thought they needed. As the narratives were rich in detail, this became a theme.

**Supports for parents living with cancer.** There were distinct differences with regard to what the parents living with cancer felt was helpful. Since her diagnosis in 2007, the parent who was actively dying found informal support of family and friends to be most helpful. In the latter stages of cancer she began to seek support,

*I’m starting to use some of the psychosocial oncology, psychiatry. I’m seeing a therapist, a relaxation therapist. So I’ve started to use some supports at Princess Margaret. (PC 1)*
She added an additional comment which captured the essence of the reality for an individual dying from advanced cancer,

_If you get really sick, you need to feel like someone’s going to take care of you. The doctor, sometimes, the oncologist, is really about treatment. And then if you have no more treatment, it’s kind of like their job is done – so you need to have somebody to take care of you._

The father diagnosed with advanced prostate cancer stated that his family was very resourceful, “and know how to navigate the system” (PC 2). Additionally, he had begun to attend a community agency that his wife and family attended. He also added that informal supports, such as family and friends, were very helpful.

When asked about supports he accessed, the other father diagnosed with advanced prostate cancer commented, “I’m an introvert – support turns me off … I don’t like people asking me too many questions” (PC 3). This father was clear about what was helpful, “My wife has been great, my close friends have been great, and my kids have been great, and that's all that I need.”

This researcher found the comments made by the young mother who was dying indicative of a significant gap in the system. She spoke clearly about the reality of being a young adult and the availability of supports during the trajectory of advanced and metastatic cancer,

_There’s not a lot out there – for young adults. … Yeah. And even, yeah, and even that group is not that big, and it’s only one. And if you go to any other metastatic group, it's always people in their 60s. Yeah. So there's nothing—you can't talk about parenting with them because it's not the same sort of thing. … I would say, I would say the majority of… the, um… I would say that there’s been times that, that, um, organizations have misunderstood or left out the need for metastatic—that, that we have different needs than the regular. (PC 4)_

Due to this gap, and her need to be with young adults in similar situations, she added, “Doctor [name of psychiatrist], um, and I started a metastatic and advanced young adult group.”

Regarding informal supports, the mother living with advanced melanoma said that for those not diagnosed with cancer the “mentality is different. Other people have a hard time understanding what you’re going through. You lose friends throughout the way. They can’t
relate or they don’t understand” (PC 5). She added that she found her psychiatrist and a community agency she and her daughter attended were beneficial. Attending groups enabled her to be in the presence of others who could relate to her situation.

The mother recently diagnosed with pancreatic cancer had accessed a significant amount of support, at PMH and in her community (nutritionist, naturopath, family and friends), “I feel very safe with the level of support. I’ve got all the bases covered.” (PC 7). Her primary concern related to supports for her children, which she perceived to be a clear void in her community.

Supports for well parents. A notable factor for the well parents in their ability to access community supports was time, or lack of it. Two parents related that they had not used supports, due to the newness of their partners’ diagnoses, and lack of time as they were caregiving, and working. One husband indicated that he felt it important to reach out for support due to the double life he led, in trying to maintain the positive outlook his wife wanted versus the reality of her status. He found the support of a psychiatrist helpful as he could openly discuss the situation. He also related that he felt supported by friends. Finally the young father’s circumstance accessing support was similar to his wife’s; being a young adult there was not much available for him. He felt that the general availability of professionals, Monday to Friday from 9:00 am – 5:00 pm was not supportive for individuals / caregivers who are parents and need to work.

If there is a support group is just inherently by our age and demographic, there’s not a lot of us. So when you do go to support groups for caregivers, they tend to be for people who are plus seventy years old. ... You know, the other problem I find with a lot of support for young adults is we all work. Um... And we all parent. So, you know, the most ideal times for us to do stuff is on a weekend, and that’s when a lot of people who are paid organizations don’t operate—because everyone works Monday to Friday. That’s their family time. So I find it interesting a lot of the times that programming will be done Monday to Friday during the day—which for the most part, other than the fact that I’ve just taken time off work because I don’t care, it’s not accessible to people in our situation. It’s a huge barrier, and it’s an obvious one. And I’ve always wondered why that isn’t like a, an automatic stop on when they’re coming up with programming. (WP 4)
Parents’ thoughts regarding supports for their children. Parents were aware of the availability, or lack of availability, of supports for their children in the community. The primary source of support was family and friends. Family members and close family friends were told quite early about the diagnosis and provided a wealth of support, from tangible aspects such as driving children to school and activities, to emotional support. This level of support was also associated with the schools and teachers. Most parents offered positive thoughts regarding the receptivity of the teachers to being emotionally present for their children, in addition to amending school work, during very stressful times.

In relation to accessing community supports for their children, there was a range among the families, echoing parents’ thoughts about their own need for support. The mother who did not access community supports, stated “there was no real need to use them, we handled this on our own” (PC 1). Family 2 and Family 5 accessed a community agency which the parents found helpful for their children who benefited from talking with other children. The parents of the six and four year old children indicated that their experience with community agencies had been mixed. In their first experience, the son participated in a group for children who had a parent with cancer. The couple, however, found the group to be confusing for their son and “not inclusive of parents dying” of cancer. Recently the family accessed an organization that provided in home support to children and parents when a parent is dying, which they felt was very helpful. Finally, the mother of the eleven year old and nine year old related her frustration about the availability of supports in her community. Living north of the Greater Toronto area, she stated that there were no supports available for families with children when a parent is living with metastatic or advanced cancer. She felt the lack of support for her children currently was a significant barrier which surprised her as she had thought her community was well resourced.
What we feel should be out there for our children. It was apparent that parents had reflected on what should be available in the community for their children. Parents stated they thought there should be more in place for children and families in clinics and the community, particularly a family therapist who specializes in supporting children and families. Following the interview with one parent, she indicated it was important that there be “someone helping children cope with the freedom to be open about stuff, and bring up questions” (PC 5).

Comments from other parents reflect similar thoughts,

I think someone to talk to, I think if there was someone at the hospital that they could go and talk to, that I would say that because they have a mom with cancer, that the doctor wants them to talk to this person about what’s going on, and I wanted them to go and it was really important they would go ... Maybe a therapist for the family. (PC 1)

There are gaps in how we support children when a parent has cancer – absolutely. Something or someone to make it seem as the world is as normal and things are as normal as possible. I was in a black hole and didn’t know and it was scary for my husband and child. Children may not voice it but they can read your face. (PC 6)

During the initial conversation with the mother who lived north of the Greater Toronto area, she echoed the benefit of a family therapist stating, “I’m greatly supported but not so for my children. Something should be in place for parents and for children” (PC 7). Following the interview, she added that it would be helpful if this individual could also come to families’ homes or clinics in the area to minimize the barrier of distance, and also when the parent is too ill to take children to sessions with a therapist.

In summary, the parents felt supports were available to them if they chose to access them. They felt informal supports, extended family and friends, in addition to the school system were beneficial for their children. Although some parents accessed community supports for their children, there was a general consensus that there needs to be more accessible community supports for children and families coping with advanced cancer, in conjunction with home visits.
The children’s perspective about supports, discussed in the following subtheme, was similar to their parents’ perspectives.

**Who can help me? Supports for children.** It was interesting for this researcher to learn the children’s own thoughts and feelings about what supports they have and need. They clearly provided insight as to what they found helpful, and what some of them felt would be helpful.

Although each resoundingly felt their parents were the most helpful, some of the children related that their friends were also helpful. The six year old said that his best friend was helpful and he liked to spend time with him, *“He understands. And he said he’s gonna give me a picture and give it to Mommy”* (CD 4). The father talked about his son’s friend in his respective interview, stating this friend was an important connection for his son. This father added that he had informed the parents of this friend about the mother’s status, in case his son talked about it.

The nine year old whose mother had melanoma related the opposite, her friends did not know and she liked it that way, *“My friends don’t know my mother has cancer – I like to keep it personal. Because I feel like that, um if I tell one person they’re going to tell someone else. I just want to be friends”* (CD 5). She added that she met friends at the community agency she went to with her mother, and they talked about their parents’ cancer.

The nine year old boy related that he found his hockey coach and team to be the most supportive. His parents talked with the coach to enable him to “keep an eye on” their son. They related they were comfortable with the team knowing about her cancer, as they felt the support would be beneficial. The coach and team members played their subsequent games with their hockey sticks wrapped in purple tape; purple is the colour of pancreatic cancer.

His eleven year old sister clearly articulated, *“I would feel better if there was another kid my age to talk to who feels the same way. I have one friend – my best friend – she tries to*
understand but she doesn’t because she’s never been through this before. But she tried her best to make me feel better” (CD 7a). Her comments may demonstrate a shift in her social location and positionality resultant from her mother’s diagnosis. Despite trying to make her feel better, her best friend didn’t understand. She felt meeting other children whose parent had cancer would be most beneficial to help her know that her thoughts and feelings about her mother’s cancer were “normal” and that other children her age understood her perspective. This child’s thoughts about meeting with other children in similar circumstances was consistent with research which will be woven into the discussion and summary in Chapter Six.

**Positives - Good Can Come From This** (Research Question 1)

“When you know your time is limited, you want to make the most of it” (PC 3). Despite the overwhelming complexities for families when a parent is living with, and dying from, advanced cancer, the literature has begun to identify positive aspects. With regard to this study, the eloquence with which the parents living with cancer spoke about the positive effects was of noteworthy, as depicted in the following, “I don’t look at the world or problems the same – things don’t bug me anymore. I stop and smell the flowers more often” (PC 5). Yes – I found my voice – [as] an advocate as young adult dying from advanced cancer. And being able to spend quality time with people – family, friends, people who I love” (PC 4).

The newest parent to be diagnosed who related that she felt the diagnosis of pancreatic cancer was related to the deterioration of her marriage over the past four years, clearly stated,

*It brought my family closer. ... I got my old husband back. The kids see us together holding hands – haven’t seen that for the last four years or so. I’m sad that it happened but hopefully our family will be much stronger, and I’m closer to my parents that are helping us.* (PC 7)

The mother who was diagnosed in 2007 and since died, related many positives which she felt stemmed from living with advanced cancer. In addition to knowing her partner and children
much better and making the most of their time together, she talked at length about what she felt was the most important positive outcome from her cancer, authentic relationships,

Well, one positive experience is that I’ve gotten very, very close to a lot of friends. I think people just cut to the chase with me. No more of this crap, airy-fairy fake life. You know, I think my relationships are much more authentic. People are around and want to be. I’m very open with people. I’m not pretending at all, [about] anything. So I’ve had a couple of people that can’t stand it and they don’t want... they’re not very authentic people. They want everything to be happy and fun and, you know, fake. And so a couple of those people I’ve really cut off my relationship or tried to. But I think with everyone else I’ve gotten much closer, much more, you know, intense, real relationships. (PC 1)

The father who was diagnosed with prostate cancer in 2006 talked at length about the positive aspects, relating that he has often thought of the ways cancer has changed his life,

When you know your time is limited, you want to make the most of it. I think I've enjoyed the last nine years more than I would have otherwise. Besides the cancer, that's always in the back of my mind, and a bit of a cloud. ... I think the good thing is, I have no doubt I know my kids a lot better now than I would have if I didn't have cancer. Not sure if it is a trade-off I’d make voluntarily, but you make the best of it. I probably know my wife better. We have had a lot more family time. I consciously spend more time with the kids – and make a point of going to their sporting events and concerts. (PC 3)

This father went on and explained what could be considered existential musing,

If there’s a definite date on which you're going to die, would you rather know it in advance or not? Would you rather be hit by a bus, with no warning – like if I'm going to die when I'm 62, would I have rather not had cancer, but got hit by a bus at age 62, no preparation, no warning, or do I prefer what I've gone through, which is I knew early I was in trouble, I could see the end is coming, and the end is there, at 62. I think I prefer my way. My circumstances. Because you do have time to adjust. I consciously did adjust, the work I did, the amount of time I spent working, the amount of time I spent with the kids.

Finally, this researcher was struck by the remarkable adaptation and resilience of each family, which could be seen as a positive outcome (Kuhne et al., 2012; Zaider et al., 2015). Despite unfathomable sadness of their circumstances, they were doing as well as they could, individually and as a family. This positive outcome, in addition to the discussion and exemplars related to this theme, represent interesting findings.
As each interview ended, the participants were asked if they had any advice for other parents, other children, or other professionals (such as this researcher). Their responses provide a unique way to summarize the analysis and interpretation.

The final words of the parents living with cancer focused on advice for other parents with cancer, specifically the importance of talking to children early and as openly as possible, “To keep kids in the dark is a bad idea” (PC 5), “[It's] easier to keep quiet about it and not say a word. It is important to talk to them, but not too much and not too early” (PC 3), “Take their lead and listen if they want to talk” (PC 6) and “Be honest with your kids to their age level explain to them in ways that they’ll understand but explain everything” (PC 7)

This researcher felt that one mother’s advice was reflective of her own struggles, “Try to take one step at a time. Not closing yourself in- Speak out get help. You don’t realize it but need it. It snowballed when I held it in. ... You have to persevere – especially if you have kids – they need our help” (PC 5).

The advice and final words from well parents focused on different aspects. The young father had the following advice, “Try to be very self-aware and give yourself some space to make mistakes ... you just kind of cope and survive” (WP 4). Another father spoke about the importance of talking to others, “Find people to talk to, not necessarily to help but to listen – Reach out to family as well if you can. Don’t push them off” (WP 6). Finally the father who struggled with the double life related that he may write a book about the complexities of caregiving and advanced cancer to help other caregivers.

The advice and final words from the children revealed what they wanted others to know, and is reflective of their authenticity, speaking openly about what was important to them.
asked what would be one thing to help a child who has a parent with cancer, their thoughts were clear, “I will say, don’t cry. Be happy, and go play” (CD 4), “To spend time with whoever [the parent] has cancer.” (CD 5), “Probably the same as what I think would help me – just talking to someone your own age – who understands and knows how you’re feeling” (CD 7a).

When asked about advice to give parents, some of their thoughts were, “You need to spend time with each other probably when the parent is not having treatment or operation going on” (CD 5), “It would be tell them that they can’t ever die. How do you know that mom may die? She has really, really bad cancer” (CD 4).

Finally their advice to professionals working with children whose parents have cancer was clear, “We need more groups for children” (CD 7a), “Like... like...like tell me that’s okay” (CD 7b). The children’s ability to clearly articulate their final thoughts provides evidence of their unique and valued role as active agents and key informants in the research process.

**Summary and Conclusion**

In reflecting on the narrative accounts of the children and parents who participated in this study, the sameness/uniqueness paradox of phenomenological research was continually evident. The sameness/uniqueness was captured in the tapestry represented by the themes and sub-themes which deepened this researcher’s analysis and interpretation. Although Gadamer contended that it is not possible to reach a definitive interpretation of a phenomenon, the analysis and interpretation of this doctoral research has advanced the understanding of the lived experiences of children and their parents when a parent is living with, and dying from, advanced cancer. This understanding was achieved through the parents’ perspectives; the parents’ perspectives of their children’s experiences; and the children’s perspectives.
Chapter Six
Summary and Discussion

The final chapter of this dissertation begins with a summary of the study and findings in relation to the research questions. Aspects of the theoretical framework evident in the findings will supplement the discussion. The second section comprises an overview of the existing empirical literature focusing on consistencies and contradictions with the findings, revealing potential contributions of this study. This section will be followed with an outline of the limitations of the study. Next will be a discussion of the implications of this doctoral study with respect to scholarly knowledge, social work practice and education, and social policy. The chapter will conclude with recommendations for future research.

Summary of the Study and the Findings

This interpretive inquiry investigated the experiences of children six to eighteen years of age and their parents coping with a parent living with, and dying from, advanced cancer (life expectancy less than twenty-four months). Conducted at the Princess Margaret Cancer Centre, seven families participated in the study, specifically seven parents living with advanced cancer, four well parents, and four children (six to eleven years). The study was informed by a review of the empirical literature (Chapter Two), in conjunction with a detailed theoretical framework (Chapter Three). Guided by hermeneutic interpretive phenomenology, an in-depth analysis and interpretation of the data revealed themes and sub-themes, which captured the essence of the participants’ lived experience, through (1) the parents’ perspectives; (2) the parents’ perspective of their children’s experiences; and (3) the children’s perspectives. Facets of the overarching theme of *Thrown into the scary, mind boggling, crazy, wide spectrum, world of advanced cancer with no return* were woven into all interviews. An additional common thread embedded in the narratives, themes and subthemes for the parents and the children was that of living as best as
they could, given the magnitude of uncertainty, distress and worry in a very changeable world. For some, this world encompassed “death’s waiting room” (Buchwald et al., 2012, p. 231).

Reflecting on findings, analysis and interpretation is a key part of this concluding chapter. This will focus on highlights of the research, followed by a reflection on the research questions in relation to the findings. Prefacing this, it is important to note that this reflection was based on the data gained from the voices of a small number of participant families. That being said, measures to ensure credibility and trustworthiness related to qualitative interpretive inquiries were established throughout the study. Furthermore, in keeping with hermeneutic interpretive phenomenology, these voices illuminated the essence of the phenomenon studied.

**Highlights of the Findings**

The following represent highlights of the findings from the three perspectives which represented the focus of this doctoral study.

**Parents’ Perspective and Parents’ Perspective of Their Children’s Experiences**

- Parents with cancer
  - Hope in an uncertain world, ardently trying to live one more day with the looming reality of death;

- Well parents
  - Chronicity/exhaustion of caregiving and parenting – a double role and balancing act while coping with the anticipated loss of his/her partner;

- Worry for the effect of cancer, anticipatory loss and treatment on the children and doing what they could to support their children;

- Responsive communication and emotional availability supported the children’s understanding, construction of meaning, and emotional security;

- Perceived changes in the attachment relationship
  - For example – the young mother’s relationship with her young children

- Positive aspects stemming from the experiences;
- Parents’ experiences with informal/formal supports - varied experiences and gaps were identified;

- Supports for young adults who are parents and availability of supports for caregivers

- Access to a clinician with experience working with children and families and knowledge of advanced cancer – to support parents in their role and children directly

**Children’s Perspective**

- All the children interviewed were affected by their parents’ cancer. However, their commentary reflected an aspect of doing as well as they could;

- The children felt they were able to talk with their parents who supported their meaning making and eased their worries through sensitive emotional attunement;

- Their parent’s cancer did have an effect on their sense of self, social location and positionality (as indicated in the ensuing discussion regarding Research Question 2);

- The children felt they needed to be strong and positive for their parents;

- Each child was very aware of what and who would be supportive;

- Some children felt their friends were helpful, but they indicated that their friends did not fully understand what it was like to live with a parent with cancer;

- Some of the children felt it was important to talk with other children, creating a sense of belonging and being understood

**Reflection on the Research Questions**

Four research questions guided this interpretive inquiry. This section will provide a discussion of each of the questions in relation to the study findings. Aspects of the theoretical framework have been incorporated into the discussion.

**Research Question 1:** How do children and their parents (ill parents and well parents/caregivers) construct meaning of the parent’s cancer?

From a social constructivist lens, construction of meaning for parents and children centered on the key aspect of living with advanced cancer or actively dying. With advances in treatment enabling individuals to potentially live longer with advanced
cancer, both phases had significant implications on the meaning the parents made, and in turn, their co-construction of meaning with their children. As noted in the exemplars and discussion, despite the parents receiving a diagnosis of advanced or terminal cancer, and knowing this would lead to their death, a definitive time line or road map did not exist, a “certain death in an uncertain time” (Kiely et al., 2010, p. 2802). A dichotomy of hope in an uncertain world framed the intent of doing whatever parents could to live as long as possible. It was not until they were told that treatment options had narrowed considerably or run out, that the reality of their death became front and center.

The narrative accounts of the ill and well parents depicted learning to live and cope as best as they could, while death loomed, and its anticipation was revisited with each change in circumstance. The commentary of the parents living with cancer reflected their struggles trying to make meaning of what was happening to them, at the prime of their lives. Well parents’ meaning was shaped by the chronicity and exhaustion of caregiving on multiple levels, in addition to a sense of loneliness. Although their narrative accounts did not depict the level of struggle voiced by their partners, the eventual loss of their life and parenting partner, and its’ effect on their children, encompassed the meaning they voiced. A common element of the meaning-making for ill and well parents was the effect of the family’s situation on the children.

With regard to the children, the co-construction of meaning each family ascribed to illness and loss was positioned in the intersubjective space shared with the ill or dying parent, well parent, and the child (children). This was evident in the perspectives of the children interviewed and the perspectives of the parents of their children’s experience. De Mol and Buysse noted the importance of children and parents as “thinking subjects” in an interactive, reciprocal
relationship in which “meanings are constructed regarding oneself and the other” (2008, p. 166-167). In keeping with Vygotsky’s sociocultural theory, each child’s meaning-making of their parents’ cancer was developed through conversations with their parents (when initially told and during the course of the illness), reflective of scaffolding. Moreover, this supported horizontal, vertical, and narrative neural integration (Siegel, 2007). Underpinning the knowledge and meaning that emerged in the relationship was the status of their parent’s disease as discussed in Chapter Five; “persons who are ‘living with a life-threatening illness [advanced cancer]’ and those persons who are ‘actively dying’” (Teno & Coppola, 1999, p. 110).

The meaning-making for three of the children interviewed was anchored in their knowledge of the parents’ status of ‘living with advanced cancer.’ Their worlds were significantly changed when they were told about and witnessed the progression of their parents’ cancer, and the effects of treatment. As they were not told of their parent’s anticipated death, it did not overtly shape their meaning-making.

For the child of the young mother who was actively dying, death did shape his construction of meaning, knowing his worlds would be forever changed. This young son was struggling to understand what his life would be like without his mother, as seen in his comments related to Harry Potter, whose parents had died. His parents’ comments were consistent with their son’s, and the father equated his understanding to a slow leak.

Being able to discuss the parent’s cancer and death (for the young family) were factors in the co-construction of this time of great uncertainty for families. Common to the meaning-making for the children interviewed were threads of worry, fear and uncertainty, interspersed with hope and the need to be strong as each child tried to do as best as he/she could.
**Research Question 2:** How do children and their ill parents, well parents or caregivers talk about coping with the parent’s cancer (specifically the threat to children’s emotional security and perceived changes to the attachment relationships, the child’s sense of self and social location)?

The foundation for the participant families’ ability to cope with a parent’s cancer was the emotional tenor and parent/child relationships prior to cancer. As the narrative accounts reflected, each parent represented an emotional anchor for their children prior to cancer, reflective of attachment and intersubjectivity and neurobiological underpinnings. This became a basis of emotional security for the children once they knew about their parent’s diagnosis and entered the world of uncertainty. Children’s accounts demonstrated that their worry about both their ill and well parent grew as they witnessed their parents’ own worry, in addition to the effects of cancer and treatment. As discussed in Chapter Five, this could be indicative of Porges’ polyvagal theory. They also stated they were able to talk with their parents who eased their worries, in essence helping to contain worry through sensitive emotional attunement. For the children interviewed, and those not interviewed but represented by their parents’ perspective of their experience, this appeared to be a pivotal factor enabling them to cope with the uncertainty of their parent’s cancer and impending loss. This could be reflective of the importance of the emotional security within the parent/child relationship acting as an “antidote for fearful or painful experiences” (Vance, 1997, as cited in Rich, 2007, p. 4).

It could be argued that there were perceived changes in the attachment relationship for some families. The youngest mother discussed the closeness of her emotional relationship with her son prior to her diagnosis when he was two years of age. She noted the shift in the mother/son relationship as her ability to parent was compromised. Regarding their young daughter, the mother and father discussed the strength of her
emotional relationship with her father. For the eighteen year old daughter who was searching to understand whether of her mother’s death was imminent, according to her father’s perspective, he related that his daughter felt comfortable in coming to him for emotional support. He added that being emotionally available to his children was important as they would grieve together as a family. Hughes stated, “Through intersubjective experiences, the subjective experiences of one contribute to the development of the subjective experiences of the others, and vice versa” (2011, p. 16).

From the children’s perspective and the parents’ perspective, the emotional security which children felt in their relationships with their parents stemmed from open and responsive communication and affective attunement between the children and their parents within the intersubjective space. As evident in the exemplars and discussion, five parents chose to tell their children about the parent’s cancer diagnosis relatively early, while two parents told their children only after a recurrence and change in treatment. Once all the children knew, their narrative accounts reflected a synchronicity with their parents’ in relation to discussions of cancer and treatment. The children related that they were able to ask questions of their parents, as more knowledgeable others (Vygotsky, 1978). They added that they felt as comforted as they could be with what their parents told them. This might be indicative of bids of the emotional connection and attachment communication between children and parents (Hughes, 2007, 2011; Schore, 2011).

Finally, changes in the child’s sense of self, social location and positionality could be seen in all children interviewed, from the six year old trying to make meaning of his life without his mother with his comments about Harry Potter; the nine year old who felt she did not want to tell her friends about her mother’s cancer as she wanted to “keep it
“personal” and just be friends, the nine year old whose team mates taped their hockey sticks in purple in support of his mother’s pancreatic cancer, or the eleven year old who ardently wanted to speak with other children her age coping with a parent diagnosed with cancer because her own friends could not understand her situation. As each child tried to cope with the changes in their family circumstances brought about by advanced cancer, his/her ‘me’, ‘you’ and ‘we’ maps are re-defined.

Parents recognized the sensitivity of the situation and the resultant changes for children in their friendships, and tried to support as best as they could. This was evident as the young parents told the parents of their son’s best friend of her impending death in case their son brought it up. The mother diagnosed with pancreatic cancer searched for community supports for her eleven year old daughter to support her in the differences she was feeling and experiencing. Again parents’ awareness of, and support for, children in this way is reflective of their emotional security and attachment relationships.

**Research Question 3:** What is the experience of children and their ill parents, well parents or caregivers with formal and informal supports within and outside the cancer centre?

a) What do children and parents find helpful and unhelpful in coping with the parent’s cancer?

A discussion of the research findings, analysis and interpretation in relation to the participants’ experiences with informal and formal supports was provided in Chapter 5. From the participants’ stories, the theme, *What’s out there to help us cope,* and the subtheme *Supports for parents living with cancer, well parents, and children* emerged.

What parents and children found helpful and unhelpful, in addition to what they considered to be gaps in community supports, will be highlighted here. With regard to informal supports, most parents and children felt extended family and friends were as
helpful as they could be. Told relatively soon after the initial diagnosis, extended family and friends supported the parents and children in both tangible and emotional ways.

There was a varied experience in relation to community supports. While not all parents accessed such supports for themselves, those who did, found them to be beneficial, particularly when attending as a family. Comments by the young couple were helpful in understanding the needs of young adults who are diagnosed with advanced or metastatic cancer and have young children. The mother’s struggles to find peer and/or professional support led her to create a group with a psychiatrist at Princess Margaret Cancer Centre. She recognized a gap in the system that was clearly apparent and worked to fill that gap. This relates to further comments made by this mother and her partner who stated that there is a great deal of support for individuals who are newly diagnosed or living with cancers with good prognoses. From their perspective, however, the degree of support is less once cancer is deemed metastatic or advanced cancer. Furthermore, based on a negative experience with a children’s group in the community, this mother indicated that supports for children should be inclusive of those whose parents will die of cancer. A final point was made by the young father about the systemic barrier to the availability of supports for caregivers in light of the demands of caregiving, in addition to working.

Perhaps the most significant thread in what the participants felt would be helpful was that of a family therapist. Several parents felt that it was important to have access to such a clinician who had knowledge of advanced cancer, in addition to experience working with children and families. Some parents felt this would be helpful in the community or home-based. This was particularly true for the family north of the GTA as the mother voiced concern regarding the absence of community supports for her family,
and as a result, the importance of home visits by a family therapist for those unable to access community supports.

**Research Question 4:** How can the experiences of both children and parents or caregivers better inform social work education and practice, in turn supporting the creation of developmentally appropriate short- and long-term support strategies for children and families coping with a parent’s advanced terminal cancer?

Although this study involved a small number of families, the voices of three significant groups were incorporated, parents living with, and dying from, advanced cancer, well parents/caregivers, and children. Moreover, in light of the in-depth engagement through hermeneutic interpretive phenomenology, participants’ thoughts and feelings voiced in their interviews offered rich and detailed information. As such, both points provide validation that the experiences of the participants will better inform social work education and practice. As this will be the focus of the final section of this chapter, only general comments will be included in this discussion in relation to this final research question.

Parents’ comments outlined with Research Question 3 define gaps in provision of service to individuals living with or actively dying from advanced cancer, and the well parents/caregivers. Another gap focused on support for parents’ roles with aspects such as the effect of advanced cancer and treatment on children, in addition to supporting their children when treatment ends and the parent’s status moves to actively dying. The most notable gap focused on appropriate supports for children themselves, whether it be in clinics, the community, or home-based. The following comment by Zaider et al. aptly captures this gap, “Because children do not typically accompany parents to oncology appointments or spend time at the bedside during a hospital admission, the parenting context is less visible to medical providers and less likely to receive attention” (2015, p. 53).
Each gap falls well within the scope of practice for social workers. A comprehensive theoretical and practical foundation must take into account the myriad of complexities, challenges and needs of children and families coping with advanced cancer and anticipated loss, which is directly applicable to social work education and practice. Such a foundation will, in turn, inform the creation of developmentally appropriate, and child/family centered strategies to strengthen families’ immediate support systems and those in communities.

**Summary of the Discussion of the Study and the Findings**

The summary of the study provided highlights of the findings, in addition to the extent to which the findings informed the research questions, thereby furthering the understanding of the experiences of children and parents coping with advanced cancer.

**Discussion of Findings in Terms of the Empirical Literature**

An extensive review of the limited, existent literature was presented in Chapter Two. Organized as a thematic review, themes located in the literature were discussed as they related to children and parents coping with the ever changing and mind boggling world of advanced cancer. This section will provide an overview of some of those themes to highlight consistencies and differences in relation to the findings, analysis and interpretation of this research.

**Anticipatory grief.** A key theme in both the literature and the research findings was that of anticipatory loss, for parents and children. Despite the status of living with, or actively dying from advanced cancer, the parents who participated in this study knew that cancer would lead to death, the worst outcome. As there is no definitive time line to death in terminal cancer, each parent was living what Bell and Ristovski-Slijepcevic described as, “coming to grips with the knowledge that it is not a matter of if their cancer will kill them, but when” (2011, p. 631). For the parents who knew their death would be all too soon, there were mixed elements of enjoying
their role as parent and partner in the time they had left, with a growing sense of needing to live as long as possible to meet milestones, and an unfathomable sadness at what they would miss.

For the youngest child interviewed, the dying time, or death’s waiting room, resembled a vast unknown. His knowledge was of life as a son, having a mother and father. He was actively grappling to understand the ramifications of life without his mother. Sheehan and Draucker noted, “Children must first cope with the illness of the parent, and then face life without him or her” (2011, p. 1058).

Finally, for all the participants interviewed who knew that death was a reality, the thought of losing one’s life, or someone loved, in addition to a way of life validate comments by Saldinger, Cain, Porterfield, and Lohnes (2004) to de-romanticize anticipated death as the good death, as discussed in Chapter Two.

**Emotional distress and living with uncertainty.** These themes of the literature were a focal point of the research findings. Distress and worry flowed through the narrative accounts of the children and parents, while coping with heightened uncertainty. This was consistent with the research which indicated that significant emotional distress in an uncertain time was felt by the parents and the children (Christ, 2000; Christ, & Christ, 2006; Kennedy & Lloyd-Williams, 2009a; Phillips & Lewis, 2015). Furthermore, each family coped with the vast unknown as a family, indicative of Mishel’s Uncertainty in Illness Theory (1988).

The literature focused on mitigating factors such as the parents’ own emotional distress and caregiver burden, which compound children’s emotional distress. It was apparent from the stories of the children and their parents that despite significant emotional distress felt by the parents, in addition to the chronicity of intense caregiving, the children’s accounts demonstrated that their parents were able to be emotionally available and attuned to their children’s worries.
The children interviewed felt supported at a level to help ease their worries. As previously indicated, there was strong indication of trusted parent/child relationships in which children’s worries were implicitly or explicitly voiced, understood, shared and supported. Moreover, a strengthening in attunement and emotional availability was reported by two ill parents, enabling them to provide increased emotional holding and containing to their children (Hughes, 2007; Schore, 2001; Tronick, 2005). This, then, makes a case in point for a contribution of this study, and further research; the importance of emotional security for children coping with the realities of advanced cancer. A caveat exists, however, with the small number of participants. Perhaps in a larger sample, the synchrony of the parent/child relationship may not be as evident.

**Caregiver burden.** This was a significant focus of the literature and evident throughout the research findings. The resounding consistency for each well parent interviewed regarding their role as caregiver, and its intensity emulated the literature. It is the research of Aamotsmo and Bugge (2014) that directly speaks to the lived experiences of the well parents/participants; “their role as a flexible ‘jelly man’ can be experienced as a stressful balancing act similar to tightrope walking, where one could easily slip and fall to either side” (p. 324). Moreover, the well parents’ level and intensity of caregiving resulted in a heightened awareness of, and availability to, their children’s physical and more importantly, emotional needs.

This, then, encompasses a further contribution of this study. Supporting caregivers who are parents will enable them to better fulfill both roles, being there for their dying partner and for their children. An additional aspect not picked up in the literature, but a focus of the findings, was the importance of supports for caregivers themselves, whether that be peer based groups, or individual support. Key to this, however, is the vital need for such supports to be available during alternate times, such as weekends, to avoid the systemic barriers discussed.
Parenting: the dying parent’s experience. This was a theme in the literature that was very consistent with the findings of the study. The commentary by parents emulated the findings of the literature. The participants’ need for normalcy was evident in research by Semple and McCance (2010) who indicated three major concerns of parents facing terminal illness. Zaider et al. noted, “The pressure felt to maintain normality is a ubiquitous theme, yet doing so becomes exponentially more difficult when disease progression brings increased fatigue, pain, and disability” (2015, p. 54). This was similar to the lived experience of the participants, particularly the two mothers who were actively dying. Research by Phillips (2014) related directly to the ill and dying parents/participants. This author discussed the theme of, “Making the Most of the Time We Have Left Together”, noting “the sicker parents became, the more parenting and their relationship with their children became a chief concern in their lives” (p. 1331). This was true for the young mother as she tried to remain alive for milestones. A divergence from Phillips’ comments, however, could be found in the mother diagnosed with pancreatic cancer in 2016. Her children became her chief concern from the moment of diagnosis, almost to a heightened level knowing the fragility of her longevity in light of the potential outcome of her cancer.

Parents’ perceptions. There was a contrast with the reviewed literature and the findings of the study as it relates to parents’ perceptions of how well their children were doing. The literature focused on the disparity between parents’ perceptions and children’s realities. Studies concluded that parents felt children were coping, when in fact the children were struggling, in addition to failure on the part of parents to recognize children’s distress (Forrest et al., 2009; Huizinga et al., 2003; Kennedy & Lloyd-Williams, 2009a; Turner, 2004). The findings of this study did not share the same conclusions.
Two points in the research stand out for this researcher. Beale (2014) concluded, “There is a common belief among parents and caretakers that children are generally adaptive and that they will adjust to their circumstances (p. 1051). This author added, “Parents and caretakers sometimes voice the belief that children, particularly younger ones, do not really understand what is going on and, therefore, it is best not to discuss the situation with them” (p. 1051). Both points were not evident in relation to the parents who participated, as evident in the exemplars. Parents were keenly aware of their children’s status, and how the course of advanced cancer and loss would affect them. With regard to the children of the youngest couple, the six year old interviewed and his four year old sister, the narrative accounts of the child, himself, and those of the young parents highlight the ability of young children’s ability to understand as best as they can. As such, even young children can, and should, be brought into the discussion, as active agents and knowers of their worlds. The importance of the inclusion of children of all ages in the family’s journey with advanced cancer, in addition to supporting parents’ ability to do so, could be considered as further contributions of this study.

**Communication.** This theme was widely researched in relation to children and families coping with advanced cancer, and anticipated loss. It was also a key theme which emerged from the findings of this study, as discussed in Chapter Five, *Difficult conversations - Telling our children what we should never have to tell them*. Research has indicated that although such conversations are extremely difficult for parents and children to have, developmentally appropriate conversations with children support their psychosocial well-being, and in turn, long-term outcomes (Beale et al., 2004; Bugge et al., 2008; Christ, 2000; Kennedy & Lloyd-Williams, 2009a; 2009b; Sheehan et al., 2014).
Although the parents stated they should never have had to have such conversations with their children, each parent added that the conversations were meaningful, and helpful for their families. From the parents’ perspectives and their perspectives of their children’s experience, it was evident that, for the most part, on-going, open communication between parents and children was part of each family’s life, prior to and during the intrusion of advanced cancer. This could represent a protective factor, or buffer, for the children, knowing that their bids of communication were welcomed, maintaining the ‘felt’ sense of emotional security. Zaider et al. (2015) validate this noting, “Families with greater cohesion and responsive communication fare better emotionally” (p. 53). Discussion of this theme in Chapter Five brought attention to the fact that the communication established with each participant family diverged from the research on communication in families coping with advanced cancer. The existing research indicated communication tended to be problematic and did not support children’s needs (Bugge et al., 2008; Forrest et al., 2009; Kennedy & Lloyd-Williams, 2009b; Turner et al., 2007).

Christ and Christ stated that it is important to “view communication as a process, not a one-time event” (2006, p. 209). An interesting facet of the research about communication centered on Ways of Telling, which stemmed from research by Sheehan et al. (2014). As indicated in Chapter Five, it was apparent that most of the parents’ communication could be regarded as Measured Telling (p. 515), and the families reported benefits similar to those indicated by Sheehan et al. From the accounts of the children interviewed, this open and appropriate communication comforted and supported them as they coped with the vast uncertainty of living with a parent who has advanced cancer.

**Role reversal.** The need to be strong and positive, in conjunction with a heightened sense of worry for not only the ill parent, but also the well parent, were threads voiced by each of the
children. Albeit only four children, their thoughts and feelings emulated that of the literature in this regard (Forrest et al., 2009; Kennedy & Lloyd-Williams, 2009a). In light of the sadness and distress/worry of the situation, it makes sense for children to worry about their parents, reflective of empathy facilitated by mirror neurons, the root of empathy. As children knew how worried they were, mirror neurons facilitated their ability to understand and feel the worry of their parents can be seen in Siegel’s comments, “We feel other’s feelings by actually feeling our own; knowing me, knowing you” (Siegel, 2010, p. 62).

The literature also noted children’s needs to hide their true emotions to protect their parents, and the need to provide emotional caregiving to both parents and in particular the well parent (Beale et al., 2004; Heiney et al., 1997; Kennedy & Lloyd-Williams, 2009b; Phillips & Lewis, 2015; Rainville et al., 2012). These points in the literature were not evident in the study’s finding as demonstrated in the children’s ability to be authentic with their thoughts and feelings. This, again highlights the contribution of this study regarding the positive outcomes resultant from the parent’s ability to give space for, and be attuned to, their child’s true self.

**Positive aspects.** In light of all that was happening for the participant families, and the tenuous future for themselves and their children, parents spoke about positives stemming from the mind-boggling world of advanced cancer. Elements of the positives reflected upon were existential musing related to meaningfulness of life, the importance of close, authentic relationships, and greater appreciation of time, especially when spent with family, and knowing partners and children on a much deeper level. Each was similar to the positive aspects outlined in the literature (Kennedy & Lloyd-Williams, 2009b; Kühne et al., 2012 Phillips, 2014; Phillips & Lewis, 2015; Sheehan, et al., 2011).
Resilience and adaptation were positive aspects interwoven in the research and hold relevance for the research participants. From the narrative accounts, the following represent snapshots of resilience and adaptation in light of overwhelming uncertainty: facing the dilatory side effects of chemotherapy if it meant living for just one more day, managing the jelly man balancing act of never-ending caregiving, rebounding as best as she could from the shock of her mother’s pancreatic cancer, knowing his teammates taped their sticks in purple in support of his mother, and the six year old trying ardently to make sense of his life without his mother, just like Harry Potter.

**Summary Findings in Terms of the Empirical Literature.** Interwoven in the discussion of the consistencies with the existing research, inconsistencies were revealed. Such inconsistencies can frame potential contributions of this doctoral study which will be outlined in the final section of this chapter.

**Limitations of the Study**

In discussing the various facets of this doctoral study, it is important to include the limitations, as there were several which further research could address.

The primary limitation was with respect to recruitment, and challenges in the process. The sample size initially proposed for this study was ten to fifteen families, however several difficulties were encountered in recruitment. At the onset of the recruitment process in May 2013, no participants enrolled in two of the studies conducted by Dr. Rodin’s research team at the University Health Network met the inclusion criteria of having children six to eighteen years of age (UHN REB 12-5609-CE or UHN REB 12-0371-CE). With regard to the additional study (UHN REB 09-0855-C), identification of patients with families meeting the inclusion criteria took considerable time due primarily to two reasons: the low number of patients identified as
having children six to eighteen years, and parents’ reluctance to consent to their child’s participation in the study.

An additional challenge in recruitment related to the level of vulnerability of patients along two lines: (1) Although some potential participants who were identified met the inclusion criteria and expressed an interest in participating, the patients felt they were too ill to participate and declined; and (2) the health status of some potential participants identified was so tenuous that they died shortly after being identified.

With respect to parents’ reluctance to consent to their child participating, Harden et al, (2000) noted that parents may act as gatekeepers, protecting their child and in turn, do not wish to give consent (as cited in Kirk, 2007, p. 1253). Christ (2000) provided a good overview of these challenges with the following:

Death is a clearly defined point of entry for research assessments, whereas the period before the death is more unpredictable in its duration and definition. Accruing patients during this often tumultuous period is extremely difficult because it requires cooperation and an excellent working alliance with the patients’ physicians who are understandably reluctant to anticipate death by three to six months. It is also extremely difficult for parents and children to commit to a study during this critical and highly stressful time. (p. 19)

Due to the sensitive nature of the study focus, the comments by Harden and Christ can apply to those potential parents who expressed hesitation in having their children participate.

As a result, discussions took place with this doctoral candidate, Dr. Faye Mishna (doctoral supervisor), and Dr. Gary Rodin to modify recruitment strategies enabling either or both parents to participate without their child (children) participating. This was in line with the inclusion criteria. In addition, it was agreed that parents of children between four to six years of age would
be able to be identified as potential participants to support recruitment. Their children, however, would not be recruited to participate as they would be too young. Finally, it was agreed that the total number of families would be reduced to six to eight families, respective of saturation. These modifications resulted in the successful identification and participation of additional parents in the study. The total recruitment and interview process spanned 32 months.

With regard to the sample, there were two limitations. First of all, while providing rich data, and being in line with the size of samples for studies incorporating phenomenological research methods, this researcher felt more representation of children and well parents would be an asset to the study. Seven parents living with cancer were interviewed, leading to a richness of stories. A sample comprised of more children and well parents, which would include families with various degrees of familial and emotional support, would bring divergent lived experience, and add to the overall analysis, interpretation, and understanding.

The second limitation with regard to the sample focuses on the homogeneity of the participant families. Aspects related to the homogeneous nature of the sample were outlined in Chapter Five. In addition to these aspects, the sample was recruited solely from the Princess Margaret Cancer Centre, Toronto. Moreover, the difficulties in recruitment affected the ability to sample theoretically. As such, it would be important in future research to recruit from different hospitals, clinics or community agencies, in conjunction with the recruitment of families representing more varied elements of subjectivity and diversity, in order to enrich the stories, analysis, interpretation, and understanding.

That being said, the aspects of diversity that existed in the sample are relevant. It is worthy of noting that as groups are never monolithic, there is no “typical” member. Divergent lifestyles and walks of life shape the lived experiences of group members. This could be applicable to the
participant families. Despite all patients being diagnosed with advanced cancer, each family made their own unique meaning of cancer and the myriad of complexities encountered. Finally, regarding the homogeneity of a sample, Smith et al. (2009) contended participants “‘represent’ a perspective, rather than a population” (p. 49).

Implications for Scholarly Knowledge, Social Work Practice, Education, and Social Policy

As noted in Chapter One, the rationale for this doctoral study focused on the advancement of scholarly knowledge and social work practice and education. This section will encompass a discussion of each, in relation to the study. In addition, this section will also include a discussion of social policy in relation to the findings of this doctoral study.

Scholarly Knowledge

Demonstrated in the extensive literature review conducted for this doctoral research, a glaring dearth exists in the empirical literature which addresses the experiences of children and parents coping with a parent living with, and dying from, advanced cancer. This dearth limits the understanding of the complexities and issues that children and parents face, in turn affecting provision of service and policy. The research findings, analysis, interpretation and summary of this study are significant in that they provide a deeper awareness of the lived experience of children and parents, and further the understanding of this phenomenon, albeit not definitive.

Contributions of this study. The following represent potential contributions of this study, which form the basis of this further understanding:

1. The importance of children’s agentic influence and participation in research;

2. Children’s need for, and parents’ awareness of, emotional security in the intersubjective space shared by the ill parent, well parent and child;

3. The role of on-going open and responsive communication and meaning-making of advanced cancer and impending loss for families;
4. The need for support for the dying parent, particularly in the anticipatory loss of their lives as partners and parents;

5. The importance of supporting caregivers in their roles as partners and parents, through illness and bereavement;

6. The importance and availability of informal and formal supports for children and parents to facilitate current coping, and short and long-term outcomes. This would also be important with respect to extended families and friends.

Social Work Practice and Education

Previously discussed in this dissertation, social work represents one of the disciplines affiliated with psychosocial oncology and palliative care in hospitals and community agencies. Because advanced cancer and anticipatory loss affects all members of the family in addition to the patient, there is a need for social workers to support children directly, and/or family members in their understanding of, and response to, children’s needs (Huff et al., 2006; Webb, 2007). As Buchwald et al. noted, “If professionals are to be able to offer good care, their knowledge of the children’s perspectives must be extended” (2012, p. 229). This was apparent in the findings of this study as parents indicated the importance of having access to a family therapist to help them in their role as parents, and to help their children.

Supporting children and families, however, is not always the mandate of busy hospital clinics, where the focus is an in-patient or out-patient basis (Beale, 2014; Rauch & Muriel, 2004). Moreover, social workers in hospital clinics may have limited knowledge of, or experience working within, a child and family perspective, especially with regard to the numerous issues faced by children coping with a parent’s cancer. This is particularly true of supporting children and families when the parent is actively dying. Dunning (2006) stated, “Anticipatory grief work with children who have a parent dying is too rarely done and even more rarely written about” (p. 511).
With respect to community agencies, as has been discussed, the significant wait times for children’s services presents a systemic barrier for families seeking support in their community. Moreover, there are very few community-based programs assisting children through a parent’s terminal illness, as validated in the findings for this study. Another option for parents seeking support in the community is that of social workers, child and family therapists, in private practice. Because such support is fee based, however, it is often out of reach for parents especially in light of the financial disparities resultant from advanced cancer.

With the above points in mind, it is important to make the needs of children and families an equal priority to patient care in hospital clinics, in addition to making services more accessible in communities.

An additional area of importance is the preparedness of social workers to provide support for children and families facing adversity, such as terminal illness and loss of a parent. Children think, and cope differently, than adults and often need their parents/guardians and other caring adults for support and guidance. This was demonstrated in the findings of the current study, especially with the children grappling with their parent’s impending death. It is critical that social workers have strong theoretical knowledge of, and clinical experience in, the provision of support to children and their parents facing overwhelming uncertainty. As noted, however, there is a lack of preparedness and confidence on the part of social workers in supporting children and families facing deeply sensitive issues (Christ, 2000; Csikai & Raymer, 2005; Huff et al., 2006; Webb, 2007, 2011).

Such knowledge and practice should be gained through graduate social work programs. Clarke and Mevik noted a “foundational professional education must equip students with knowledge, skills and attitudes that enable them to work with and for this population” (2008, p.
Research, however, indicates there is minimal social work education that addresses responding to children’s psychosocial needs during crises and the provision of realistic intervention strategies facilitating positive outcomes (Luckock, Lefevre & Tanner, 2007; Mullin & Canning, 2006). As such, social work students, and in turn practitioners, may have difficulty following a child’s lead, maintaining a child perspective in providing interventions, and developing the emotional capacity to ‘be there’ with children in times of distress. This is even more so in the area of psychosocial oncology and palliative care, particularly when a parent is living with, and dying from, advanced cancer.

These arguments corroborate the finding of the current study providing impetus for the development of social work curriculum to enable clinicians to meet the myriad issues facing children and families in crisis, particularly coping with the uncertainties of advanced cancer and death’s waiting room. The knowledge and skills gained through such curriculum development will facilitate and inform the creation of effective programs supporting positive short- and long-term for children and families.

**Social Policy**

In discussing the scholarly knowledge, and social work practice and education, it is also important to focus on social policies in relation to advanced cancer, dying and death as faced by children and families. Two aspects are of significance; the status of children’s mental health in Ontario, and medically assisted dying.

**Children’s mental health in Ontario.** The difficulties in accessing children’s mental health services in Ontario were outlined in Chapter One with statistics included from The *Pre-Budget Submission 2016 for Children’s Mental Health Ontario*. Since the publication of that document, there has been a dramatic increase in wait times as well as the number of children and
youth waiting for services for mental health support. The advocacy agency, Children’s Mental Health Ontario (CMHO), indicated that as of November 2016, “Only one in six young people who need mental health services receives them.” Additionally, “children and youth in urgent need of mental healthcare are waiting up to 1.5 years for treatment in some parts of the province” and, the number of children waiting for service is “on the rise with nearly 12,000 kids waiting for long-term psychotherapy” (2017, para. 1). As such, Kim Moran, CEO of CMHO stated, “Unacceptable wait times and insufficient access to mental health professionals have created a crisis. Many families are struggling tremendously because of this lack of access to care. We can’t let this continue any further – our children deserve better” (CMHO, 2017, para. 2).

The need for realistic and timely support for children and their families coping with advanced cancer and pending loss have been documented in the literature. Moreover, this was clearly voiced by children and parents participating in this doctoral study. Although children may be coping as best as they can, and are able to look to parents and caring adults for support, having access to appropriate mental health supports is a key prevention strategy. This can be to support children directly and/or parents in their ability to be available for their children’s needs.

Furthermore, not all children do well and many struggle, as evident in the literature. In such cases, access to readily available children’s mental health services is a critical. Such long wait times and limited accessibility to children’s mental health services, however, represent an additional disparity for children and families at such a vulnerable time. This added disparity only serves to magnify the potential disparities posed by advanced cancer (as discussed in Chapter One), and reinforce the tenuousness and vulnerability encompassing their lived experience.

Medical assistance in dying. According to the Government of Canada, following the Supreme Court of Canada’s ruling that prohibiting assisted dying was unconstitutional, Bill C-
Medical Assistance in Dying (MAID) received royal assent and became law on June 17, 2016 (“Medical assistance in dying”, 2017, para. 1). As indicated in the government publication, *Legislative Background: Medical Assistance in Dying (Bill C-14, as Assented to on June 17, 2016)*, Subsection 241.2(1) outlines the following eligibility criteria for MAID:

- be eligible for health services funded by the federal government, or a province or territory;
- generally, visitors to Canada are not eligible for medical assistance in dying;
- be at least 18 years old and mentally competent. This means being capable of making health care decisions for yourself;
- have a grievous and irremediable medical condition;
- make a voluntary request for medical assistance in dying that is not the result of outside pressure or influence;
- give informed consent to receive medical assistance in dying. (2016, page 9)

This legislation has potential implications for children and families coping with terminal cancer and anticipatory loss. Terminal cancer represents a grievous and irremediable medical condition. Moreover, Heidegger (1927/1996) suggested that humans are the only living creatures who have the capability of contemplating the possibility of non-existence, or death. Therefore, the uncertainty of the dying time may become more certain for parents who choose to seek medical assistance with their death. The date of a parent’s death will be known in advance, and in this light, support for children and families should be taken into consideration by medical professionals offering such assistance to the dying.

As health professionals are obliged to engage in discussions with patients who seek assisted dying, MAID has implications for social workers supporting children and families coping with advanced cancer, particularly parents who wish to seek medical assistance with their death. This is significant for social workers who are members of interdisciplinary teams in hospital settings. The Ontario College of Social Workers and Social Service Workers (OCSWSSW) states, “MAID is an intense and sensitive issue, which undoubtedly will have a
profound impact on those who are involved with it” (2016, p. 5). The scope of practice of social workers encompasses supporting an individual’s right to self-determination, in addition to making decisions based on voluntary, informed consent, both of which apply directly to MAID.

As such, social workers may provide support to parents who wish to know more about, or receive, medical assistance with their death. Social workers may also with the children, partners, and family members of a parent wishing to end his/her life with medical assistance. With regard to the extent of involvement of a social worker in MAID, the OCSWSSW indicates, “The member may provide information to the patient, and refer them to the appropriate doctor or nurse practitioner regarding next steps. However, it remains a crime to counsel a person to die by suicide” (2016, p.13). Finally, MAID may present potential implications for the personal values and beliefs of a social worker supporting children and families.

**Implications for Future Research**

The focus and results of this doctoral research hold implications for future research. The first implication is the mere fact that more research must be conducted. This is especially true in consideration of the meager existent research in contrast to the importance of this time for children and families. This study demonstrated that children and parents have much to say if given the opportunity to do so in safe disclosive spaces. Additional qualitative research will add to the understanding of this phenomenon presented in the study.

Working to develop strategies that will ease the difficulties in recruitment this doctoral student experienced is another important implication for future research. Looking for different ways to involve children may support parents in providing their consent for their children’s participation. Focus groups with parents, for example, may be a useful starting point, enabling parents to understand the valuable inclusion of the voices of their children and youth in research.
Stemming from this, focus groups with children and youth themselves may represent a further way to gain an understanding of their lived experiences. Additionally, recruiting from different hospital settings as well as community agencies, urban and rural, will enhance the rich data that can be gained in future research. Related to this is the importance of increasing the diversity of participants within the sample itself through the use of theoretical sampling. It is vital that representation be as inclusive as possible.

There is a need for future research in relation to cancer health disparities, advanced cancer and parenting. As indicated in Chapter One, these disparities are significant to the treatment and well-being of individuals living with cancer. However the research has not yet focused on the effect of these disparities on families coping with advanced cancer.

Finally, future research can play a role in the provision of meaningful and realistic supports for children and families, specific to their needs from diagnosis to the dying time and bereavement. This may begin with social work education and the inclusion of the needs of children and families in the social work curriculum, and continue with professional development for registered social workers practicing in a variety of settings.

**Conclusion**

“Life is inherently uncertain and unpredictable, with or without cancer” (Kiely et al., 2010, p. 2804). As emotional distress is considered to be the sixth vital sign, psychosocial oncology has a significant role to play in supporting families through the illness trajectory of advanced cancer, palliative care and death. The existent research, however, touched the surface with regard to the needs affecting the provision of support to children facing the loss of a parent and emotional security. Through hermeneutic interpretive phenomenology, the results of the study begin to address the gaps in the literature and advanced understanding of the co-
construction of meaning of this sensitive time as it relates to the dying parent, the well parent, and the child. The integration of relational perspectives and social constructivism and social learning theory, in conjunction with interpersonal neurobiology, represented an insightful way of developing a greater understanding of this compelling issue.

The benefits of this research are far reaching. Focusing on the lived experiences of children and parents coping with the uncertainty of advanced cancer and anticipatory loss, this doctoral study added the voices of eleven parents and four children to the small body of research, and provided further understanding of the experiences of children and their parents. Moreover, the stories of participant families illuminated the importance of emotional security and attunement in parent/child relationships. Each child’s meaning-making of their parents’ cancer was supported through conversations with their parents (when initially told and during the illness). Changes in the child’s sense of self, social location and positionality could be seen in all children interviewed. In addition, this study identified gaps in services supporting parents and children, specifically services for young adults who are parents; caregivers who are over-burdened; supports for children. This study also hold relevance for social work education and practice, and encouraging policy and service revisions, thereby enabling families and professionals to create safe spaces for children during this traumatic time.

Finally, and perhaps most importantly, this study confirmed children’s agentic influence and authentic voices as integral part of families, and it is important that “we, as ‘not-knowing adults’, are prepared to learn from children” (De Mol & Buysse, 2008, p. 190).
References

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Note: Appendices D – S above were created in relation to the Study Protocol (Appendix C) submitted for University Health Network REB and Institutional approval. Each has the official formatting (header and footer) required for document submission. Page numbers have been added in reference to the Table of Contents for this doctoral thesis.
Notification of REB Initial Approval

Date: December 2nd, 2013
To: Dr. Gary Rodin
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Re: 13-6188-CE
Living with Uncertainty: Psychosocial Needs of Children Coping with a Parent’s Cancer

REB Review Type: Expedited
REB Initial Approval Date: December 2nd, 2013
REB Expiry Date: December 2nd, 2014

Documents Approved:

- Protocol
- Consent Form - Accompanying Adult
- Consent Form - Parents
- Consent Form - Children 6-16
- Consent Form - Children 17-18
- Volunteer/Community Service Letter
- Telephone Recruitment Script
- Recruitment Letter for Health Care Professionals
- Parent or Caregiver Distress Rating Scale
- Worry Meter for Children
- Introductory Recruitment Letter for Parents
- Interview Guide - Child
- Interview Guide - Parent with Cancer
- Interview Guide - Well Parent or Caregiver
- Demographic Information Form - Child
- Demographic Information Form - Well Parent or Caregiver
- Demographic Information Form - Parent Living with Cancer
- Illness Time Line
- Condolence Letter Template
- Thank You Letter Template

Version date: November 25th, 2013
Version date: November 25th, 2013
Version date: November 29th, 2013
Version date: November 29th, 2013
Version date: November 25th, 2013
Version date: September 12th, 2013
Version date: September 12th, 2013
Version date: September 12th, 2013
Version date: September 12th, 2013
Version date: September 12th, 2013
Version date: September 12th, 2013
Version date: September 12th, 2013
for Good Clinical Practice E6(R1); Ontario Personal Health Information Protection Act (2004); Part C Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations and the Medical Devices Regulations of Health Canada. The approval and the views of the REB have been documented in writing.

Furthermore, members of the Research Ethics Board who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

Best wishes on the successful completion of your project.

Sincerely,

[Signature]

Jack Holland, MD FRCPC
Co-Chair, University Health Network Research Ethics Board
PROTOCOL REFERENCE # 29775
January 10, 2014

Dr. Faye Mishna    Ms. Gabrielle Erica Pitt
FACULTY OF SOCIAL WORK  FACULTY OF SOCIAL WORK

Dear Dr. Mishna and Ms. Gabrielle Erica Pitt,

Re: Administrative Approval of your research protocol entitled, "Living with uncertainty: Psychosocial needs of children coping with a parent's cancer"

We are writing to advise you that the Office of Research Ethics (ORE) has granted administrative approval to the above-named research protocol. The level of approval is based on the following role(s) of the University of Toronto (University), as you have identified with your submission and administered under the terms and conditions of the affiliation agreement between the University and the associated TAHSN hospital:

- Graduate Student research - hospital-based only
- Storage or analysis of De-identified Personal Information (data)

This approval does not substitute for ethics approval, which has been obtained from your hospital Research Ethics Board (REB). Please note that you do not need to submit Annual Renewals, Study Completion Reports or Amendments to the ORE unless the involvement of the University changes so that ethics review is required. Please contact the ORE to determine whether a particular change to the University’s involvement requires ethics review.

Best wishes for the successful completion of your research.

Yours sincerely,

Daniel Gyewu
REB Manager
QUALITATIVE STUDY PROTOCOL

LIVING WITH UNCERTAINTY:
PSYCHOSOCIAL NEEDS OF CHILDREN
COPING WITH A PARENT’S CANCER

Principal Investigator:
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Study Delegate:
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Princess Margaret Cancer Centre
University Health Network

25 November 2013
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Protocol Summary

Full Title
Living with Uncertainty: Psychosocial Needs of Children Coping with a Parent's Cancer

Short Title
Psychosocial Needs of Children Study

Type of Study
Qualitative Hermeneutic Phenomenological Study

Sample Size
N = 10 to 12 families

Study Population
Patients with advanced or life limiting cancer (broadly corresponding to an expected survival of less than 6 to 24 months), with one or more children age 6-18, and their families will form the basis of the study population. Specifically the children, their ill parent, and their well parent or caregiver will be invited to participate. Dr. Gary Rodin (study PI) and his team at the Princess Margaret Cancer Centre are currently approaching patients with metastatic and advanced cancer for three studies at the Princess Margaret Cancer Centre. These studies include: (1) UHN REB 12-5609-CE: A study of physical and psychological symptoms in patients with pancreatic and other gastrointestinal cancers (G. Rodin, PI; P. Fitzgerald, Co-I); (2) UHN REB 09-0855-C: A randomized controlled trial of a brief psychotherapy referred to as Managing Cancer and Living Meaningfully (CALM) for patients with metastatic cancer (G. Rodin, PI; S. Hales, Co-PI); and (3) UHN REB 12-0371-CE: A study of the experience of advanced cancer in young adults (G. Rodin, PI; M. Knox, Co-I). A linkage between these studies for the purpose of identifying patients who meet the inclusion criteria for the present study (a parent with advanced cancer; a well parent or caregiver; child/children age 6-18 years; English-speaking) will be established and this information provided by Dr. Rodin’s study team to Gabrielle Pitt (PhD Candidate) for possible recruitment to the present study. In addition, health professionals (oncologists, physicians, psychiatrists, psychologists, nurses, and social workers) working with patients diagnosed with advanced cancer at the Princess Margaret Cancer Centre will be consulted by letter and invited to identify families fitting the inclusion criteria.

Note: As it is important to note that the adult supporting the parent with advanced cancer and child (children) may not be a parent, the use of the term well parent or caregiver is inclusive of biological parents and alternate caregivers.

Accrual Period
1 year

Study Design
As a qualitative study, the research design for this study will be informed by interpretive hermeneutic phenomenology and incorporate a thematic analysis. The method of data collection will be semi-structured interviews with children and parents separately (however children will be given the option of completing their interview alone or with a companion present; a trusted adult
other than the parent whom the child would feel most comfortable with such as an adult sibling, 
aunt, uncle, cousin, or the person caring for the child. Results from this study will increase the 
understanding of children’s psychosocial needs, inform social work education and practice, and 
facilitate the development of appropriate interventions promoting positive outcomes for children 
and families coping with a parent’s cancer.

**Study Duration**
December 2013 to December 2014

**Study Agent/ Intervention/ Procedure**
Name, Dose, Duration, Frequency, Route of Administration
Not Applicable - this study will not involve an agent/intervention/procedure.

**Study Objectives**
Through qualitative research design, the primary objectives of this study are:

a) to develop a greater understanding from children and parents or caregivers of their 
experiences of coping with a parent’s advanced cancer with a life expectancy of less than 
6 - 24 months (specifically worry or distress, the threat to children’s emotional security 
and perceived changes to the attachment relationships);

b) to provide current and relevant research informing the identified gaps in the literature;

c) to provide greater awareness of appropriate short and long terms supports for children 
and parents or caregivers coping with a parent’s advanced cancer; and

d) to inform social work education and practice with respect to supporting children and 
families coping with this situation.

**Endpoints of the Study**
A detailed understanding reflective of the experience of a parent’s advanced cancer from the 
perspective of the children and their parents or caregivers represents the endpoint of this study. 
As this is a qualitative study, an important criterion of this endpoint will be when saturation is 
achieved, and “no additional data are being found whereby the researcher can develop properties 
of the categories” (Strauss & Corbin 1998, p. 61).
Living with Uncertainty: Psychosocial Needs of Children Coping with a Parent’s Cancer

1.0 General Information
1.1 Protocol title and date
Living with Uncertainty: Psychosocial Needs of Children Coping with a Parent’s Cancer
Version date: 12-September-2013

1.2 Name and title of the investigator(s) who is (are) responsible for conducting the trial/study, and the address and telephone number(s) of the trial/study site(s).
Principal Investigator:
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2.0 Background Information
2.1 Background of the study:
“Cancer invades the family; not just the diagnosed patient’s body” (Lewis, 1990, p.752). The course of a parent’s advanced cancer is a time of considerable uncertainty and distress for those involved, especially the children in the family. The treatment and its side effects, frequent absences of one or both parents, and caregiver burden, can be worrisome for children six to eighteen years of age, and their impact can reverberate throughout the family. A parent or attachment figure represents someone on whom the child can rely for support, an emotional anchor. When the parent who represents such an attachment figure is coping with advanced terminal illness, the child faces not only the distress created by the illness, but also the threat of losing a parent. Moreover, the well parent or caregiver may be affected by this circumstance such that their parental efficacy and emotional availability to the child is diminished. Research indicates that children are a hidden high risk group and that the fear of losing their parent in this situation is more problematic than the actual loss of a parent (Beale, Sivesind, & Bruera, 2004; Bugge, Helseth, & Darbyshire, 2008; Christ, 2000; Christ, & Christ, 2006).
Advances in psychosocial oncology and palliative care have led to improvement in addressing the needs of patients with advanced cancer and their caregivers (Bultz & Carlson, 2006; Gelfman, Meier, & Morrison, 2008). Yet advances in supporting the psychosocial needs of children coping with a parent’s terminal cancer lag behind (Rauch & Muriel, 2004; Wilkins, Quill, & King, 2009). The psychosocial needs of children six to eighteen years of age are complex, which may account for their heightened vulnerability (Christ, 2000).

Due to the potential consequences on children of living with a parent’s terminal illness and anticipated death, parents often seek community supports to help the child through this time of crisis. Social workers represent such a support helping children through crisis intervention, and short-term and/or long-term counseling (Huff, Weisenfluh, Murphy, & Black, 2006). With respect to oncology and palliative care, social workers play a significant role in working with the ill patient and his/her family; they provide individual and family support with regard to psychosocial and possibly end-of-life issues, in addition to community resources (Blacker & Deveau, 2010; Meier & Beresford, 2008). However, there is a lack of educational preparation for clinicians about issues of life threatening illness, dying and death. As a result, social workers may experience “a strong sense of helplessness” (Huff et al, 2006, p. 222), and are often “not as prepared as they need to be or would like to be to be” (Csikai & Raymer, 2005, p. 53). This helplessness and unpreparedness can be magnified with regard to the care of children. Developing a comprehensive theoretical and practical foundation for support of children living with a parent who has advanced cancer could be an important contribution to social work education and practice.

There is a glaring dearth in the theoretical and empirical literature addressing the psychosocial needs of children living with a parent with terminal cancer. Only in the past decade has research begun to emerge regarding this sensitive time for children and families.

2.1.1 Emotional distress
Distress experienced by individuals living with cancer and their family members, specifically informal caregivers, has become the subject of recent empirical research (Dumont et al 2006; Given, Given, & Kozachick, 2001; Rodin et al 2009; Wilkins, Quill, & King, 2009). As a result, emotional distress has been recognized as an indicator of psychosocial well-being and has been deemed the sixth vital sign (Bultz & Carlson, 2006). Research has identified that children who have a parent diagnosed with terminal cancer experience greater psychosocial vulnerability, high levels of distress, depression, anxiety, and lower self-esteem which can be compounded by the parent’s own emotional distress (Beale et al, 2004; Bugge, Helseth, & Darbyshire, 2008; Christ, 2000; Christ & Christ, 2006; Kennedy & Lloyd-Williams, 2009a, 2009b; Rauch & Muriel, 2004; Turner, 2004).

2.1.2 Anticipatory loss
A significant aspect of living with advanced cancer is the ever-present realization that the parent will die of their disease. Kiely, Tattersall, and Stockler conceptualize this realization as, “a certain death at an uncertain time” (2010, p. 2802). With regard to children, their worry about the death of their parent can be overwhelming. Research has confirmed that anticipating the death of a parent is magnified for children and complicated by their developmental limitations in understanding the impending death (Saldinger, Cain, Kalter, & Lohnes, 1999; Saldinger, Cain,
Porterfield, & Lohnes, 2004; Turner, 2004). Therefore, the terminal phase of a parent’s illness may be a period of greater psychological stress for children than the actual loss and bereavement, having detrimental implications on children’s post-death grief and long term outcomes (Christ, 2000; Christ & Christ, 2006; Dunning, 2006; Kennedy & Lloyd-Williams, 2009a; Saldinger, Cain, Kalter, & Lohnes, 1999; Saldinger, Cain, Porterfield, & Lohnes, 2004).

2.1.3 Caregiver burden
In families with children, the caregiver for a parent living with advanced cancer is often the well parent. Such individuals often take on the double role of caring for both children and the parent who is coping with terminal illness. Studies conclude that parents or caregivers have as much or even higher distress than patients and may experience caregiver burden (Dumont et al, 2006; Given, Given, & Kozachick, 2001; Grunfeld et al, 2004). Dumont et al. (2006) summarized the detrimental effects of caregiver burden indicating that “caregivers should not be considered only as partners in caring but also as potential patients” (p. 918). Caregiver distress and burden are cumulative risks that have significant consequences to parenting efficacy, affecting the emotional well-being of the children. Rauch and Muriel (2004) contend that while acting as a caregiver and parent, the well parent’s sense of competence to meet their children’s needs declines, especially with regard to emotional sensitivity, responsiveness, and discipline. If the parent is depleted emotionally and physically, there is a negative spin-off for children’s ability to cope with the complexities and uncertainties of a parent’s advanced cancer and future outcomes (Dunning, 2006; Saldinger, Cain, Porterfield & Lohnes, 2004).

2.1.4 Communication
Kennedy and Lloyd-Williams, (2009b) conclude that communication is a critical aspect to positive outcomes for children. Children may want or seek information about their parent’s cancer from their parents, and factual information from health professionals, books, and the Internet. Forrest, Plumb, Zieland, and Stein (2009) contend that children’s reactions are exacerbated if the parent/child communication is impeded. Further research has indicated that communication is often interrupted by parents withholding information because they fear this information will create further distress for their children (Fearnley, 2010; Hilton & Elfert, 1996; Walsh, Manuel, & Avis, 2005).

2.1.5 Role reversal
Role reversal, identified as emotional responsibility of children for parents, may occur in the context of advanced disease (Forrest, Plumb, Zieland & Stein, 2009; Kennedy & Lloyd-Williams, 2009a). Furthermore, children may feel the need to convey strength to protect their parents from further stress (Christ & Christ, 2006; Kennedy & Lloyd-Williams, 2009b; Winnicott, 1965). This may protect the child from overwhelming feelings of helplessness and from concern about the parents’ vulnerability (Christ & Christ, 2006; Forrest, Plumb, Zieland & Stein, 2009; Kennedy and Lloyd-Williams, 2009a).

2.1.6 Parental perceptions
The literature indicates that parents and family members tend to underestimate the degree of impact of the parents’ advanced cancer has on their children. Turner notes, “Although the emotional burden for families and children of young mothers with advanced breast cancer is considerable, it appears that parents may fail to recognize or respond to this distress” (2004, p.
61). With regard to the father/child relationship, Forrest, Plumb, Zieland, and Stein (2009) found a disparity between the perceptions of fathers and their children. Fathers tended to underestimate children’s distress, presuming that this reassured their children, even though children did not indicate that they felt reassured. Kennedy and Lloyd-Williams (2009a) also found that parents underestimated the impact of a parent’s terminal status on their children.

Although there has been some research examining the issues faced by children and families coping with advanced cancer of a parent, there has been a notable lack of attention to the meaning children make of terminal cancer in a parent and its emotional impact on them. This paucity of research limits the parental and professional understanding of this sensitive issue for children (Christ, 2000; Forrest, Plumb, Zieland, & Stein 2009; Kennedy & Lloyd-Williams, 2009a).

2.2. Rationale for the study
Children are deeply affected by cancer in a parent, but there has been little research on its immediate or long-term impact on them. The limited research confirms that there is potential for children’s developmental outcomes and well-being to be compromised due to the potential consequences of living with a parent’s terminal illness, and their anticipated death (Beale et al, 2004; Bugge, Helseth, & Darbyshire, 2008; Christ, 2000; Forrest, Plumb, Zieland & Stein, 2009; Kennedy & Lloyd-Williams, 2009a, 2009b; Rauch & Muriel, 2004; Turner, 2004).

There is a need for critical research incorporating the voices of children and their parents or caregivers to fully comprehend the complexities of advanced terminal cancer faced by families, particularly with respect to worry or distress, threats to emotional security, and changes in attachment relationships. Christ (2000) made a case for such research, stating that a clear understanding of children’s psychosocial needs may be missed if the period before the death is left out of the research. Results from this study will address the concerning gaps in the literature by increasing the understanding of children’s psychosocial needs, and providing new insight specifically to the meaning children and parents ascribe to this sensitive time, threats to emotional security, and the role of parents or caregivers in understanding the nature of, and ameliorating, potential effects to children.

Additionally, developing a comprehensive theoretical and practical foundation to support families coping with advanced terminal cancer will inform social work education and practice, thereby enhancing the creation of developmentally appropriate, and child/family centered strategies. Such strategies will strengthen immediate support systems and communities to help them better meet the needs of children during this time of heightened distress, improving short-and long-term outcomes for children and their families.

2.3 A summary of the known and potential risks and benefits, if any, to human subjects.

2.3.1 Potential Risks
Participants may experience difficulty emotionally when answering questions in the interview. Participants can choose not to answer any questions or the interview can be stopped. Participants can choose to continue the interview at that time, or another time that is convenient, or participants can choose not to continue the interview at all. The treatment patients receive will
not be affected if they chose to end the interview. Participants can talk about their concerns with this doctoral candidate (Gabrielle Pitt) at any time. If participants feel they or their children need further support, a referral can be made for counselling services. Such services could be available through the patient’s oncology clinic, and the Department of Psychosocial Oncology and Palliative Care at the Princess Margaret Cancer Centre. Partners or caregivers of patients at Princess Margaret can also be referred to the Department of Psychosocial Oncology and Palliative Care. For children and well parents or caregivers, referrals can also be made through regional mental health agencies, family services or licensed private practitioners. There are no potential risks to the community/public, or to the institution.

2.3.2 Potential Benefits
Although participants may not directly benefit from participation in this study, the information collected will help patients and their families in the future. A potential benefit may lie in the opportunity for children’s voices to be heard. Often children are not given a chance to tell others how they feel, and what they need to help them with what is happening to their parent. The increased understanding of the meaning of the experience of children represents potential benefits to participants.

An additional benefit will be that the understanding of the experiences of children and parents or caregivers will inform social work education and practice, addressing the lack of preparedness identified in the literature through curriculum and professional development. This will contribute to the creation of developmentally appropriate child and family centred short- and long-term support strategies. Such strategies will assist immediate support systems and communities in better meeting the needs of children and families experiencing the distress of advanced cancer, and the uncertainty of shortened life expectancy.

Finally if the participant is a teenager, he or she will receive a volunteer/community service letter to recognize the time he/she volunteered to participate in the study (2 hours) which he/she could use toward his/her community service hours if he/she chooses (Appendix 19).

2.4 Description of the population to be studied.
Patients with advanced cancer with an expected survival of less than 6 to 24 months, well parents or caregivers, and their children (6 to 18 years of age) will form the basis of the study’s participants. Ten to twelve families is the expected sample size, enabling a rich understanding of the essence of the participants’ experiences which is fitting with phenomenological research (Creswell, 2002; Kreuger & Neuman, 2005; Smith, & Osborn, 2007). The actual sample size will be determined when saturation or redundancy of information is achieved (Strauss & Corbin, 1998).

3.0 Study Objectives and Hypothesis
3.1 A detailed description of the objectives and the purpose of the study.

3.1.1 The purpose of this study
The purpose of this qualitative study is to incorporate the voices of children and parents or caregivers using interpretive hermeneutic phenomenology to develop a rich and varied understanding of the lived experiences of children six to eighteen years of age and their parents.
or caregivers when a parent has been diagnosed with advanced cancer (life expectancy of less than 6 - 24 months). This understanding will inform social workers and professionals working in oncology and palliative care in the creation and provision of developmentally appropriate interventions for children and families, thereby supporting short- and long-term outcomes.

3.1.2 Primary objective
The primary objective is to develop an in-depth understanding of the experiences of children six to eighteen years of age, and their parents or caregivers coping with a parent’s advanced cancer and potentially, attachment and anticipatory loss. The understanding will address gaps in the literature, inform social work education and practice, and support short- and long-term outcomes for children and parents.

3.2 Study hypothesis
As qualitative research is inductive, interpretive and constructive, a study hypothesis is not applicable.

The research questions guiding this interpretive inquiry are:
1) How do children six to eighteen years of age and their ill parents, well parents or caregivers construct meaning of the parent’s cancer?
2) How do children and their ill parents, well parents or caregivers talk about the parent’s cancer (specifically their worry and distress, the threat to the child’s emotional security and perceived changes to the attachment relationships, the child’s sense of self)?
3) What is the experience of children and their ill parents, well parents or caregivers with formal and informal supports within and outside the cancer centre?
   a) What do children and parents or caregivers find helpful and unhelpful in coping with the parent’s cancer?
4) How can the experiences of both children and parents or caregivers better inform social work education and practice, which will lead to creation of developmentally appropriate short- and long-term support strategies for children and families coping with a parent’s advanced terminal cancer?

4.0 Study Design
The scientific integrity of the study and the credibility of the data from the study depend substantially on the study design. A description of the study design should include:

4.1 A specific statement of the primary endpoints and the secondary endpoints, if any, to be measured during the study.
The primary endpoint of this qualitative study is a detailed understanding of the experience of children and their ill parents, well parents or caregivers. In this qualitative study, the endpoint will occur when saturation is achieved, and “no additional data are being found whereby the researcher can develop properties of the categories (Strauss & Corbin 1998, p. 61).
4.2 A description of the type/design of the study to be conducted (e.g., interventional or observational; double-blind, placebo-controlled; parallel design etc.) and a schematic diagram of study design, procedures and stages (e.g. screening, baseline, study intervention, follow-up period)

A Qualitative Hermeneutic Phenomenological Study
Methodological Rationale
Qualitative methodology is appropriate for this inquiry as it captures the essence of the participants’ experiences through rich narratives (Durrheim, 2006; Kvale, 1996). Moreover, MacKay, Greig and Taylor note, “children represent an excellent source of the kind of data that are at the heart of qualitative research – rich descriptions in words and pictures that capture children’s experiences and understandings” (2007, p. 138).

The research design will be informed by hermeneutic interpretive phenomenology; a methodology that is used to explore questions of meaning and gain an understanding of how people make sense of their experiences (Cohen, Kahn, & Steeves, 2000; Crist & Turner, 2003; Moustakas, 1994; Smith, 2003). Hermeneutic interpretive phenomenology informed by the work of Gadamer (1960; 1976; 1983; 1998) is viewed as the most appropriate methodology for this proposed study because it is congruent with the research questions aimed at uncovering and developing a deep understanding of the complexities and meaning of the experiences of children and parents coping with incurable illness such as advanced cancer.

Data Collection
This study will be conducted at the Princess Margaret Cancer Centre, University Health Network. Patients with terminal cancer with an expected survival of less than 6 to 24 months, and their families will form the sample; specifically children, six to eighteen years of age, their well parents or caregivers and their ill parents. Dr. G. Rodin’s research team at the Princess Margaret Cancer Centre has begun approaching patients with advanced cancer for three studies. These studies include: (1) UHN REB 12-5609-CE: A study of physical and psychological symptoms in patients with pancreatic and other gastrointestinal cancers (G. Rodin, PI; P. Fitzgerald, Co-I); (2) UHN REB 09-0855-C: A randomized controlled trial of a brief psychotherapy referred to as Managing Cancer and Living Meaningfully (CALM) for patients with metastatic cancer (G. Rodin, PI; S. Hales, Co-PI); and (3) UHN REB 12-0371-CE: A study of the experience of advanced cancer in young adults (G. Rodin, PI; M. Knox, Co-I).

A linkage between these studies for the purpose of identifying patients who meet the inclusion criteria for the present study (a parent with advanced cancer; a well parent or caregiver; child/children age 6-18 years; English-speaking) will be established and this information provided by Dr. Rodin’s study team to Gabrielle Pitt (PhD candidate) for possible recruitment to the present study.

Further, as additional potential sources of participant families, health professionals (oncologists, physicians, psychiatrists, psychologists, nurses, and social workers) working with patients diagnosed with advanced cancer at the Princess Margaret Cancer Centre will be consulted to identify families fitting the inclusion criteria (see Consent Process for further details).
The sample size will consist of ten to twelve families with each family having one child between six to eighteen years of age, the well parent or caregiver, and potentially the ill parent (dependent on the ill parent’s ability to take part in an interview due to their disease progression). If there is more than one child in a respective family, purposive sampling will be used to determine whether the additional children in the family will be interviewed. This sample size is appropriate for a phenomenological study with the goal of obtaining a varied, rich and deep understanding or essence of the participants’ experiences (Creswell, 2002; Kreuger & Neuman, 2005; Smith, & Osborn, 2007).

Data collection will begin with parents completing Demographic Information Forms for themselves and for the child (children) (Appendices 8, 9, and 10). This basic demographic information (at the lowest level of identifiability possible) is to provide background for each participant prior to the interviews. Digitally audio recorded face-to-face semi-structured interviews with children, well parents or caregivers, and possibly the ill parents will form the primary basis of the data collection. The interviews will take place separately (however children will be given the option of completing their interview alone or with a companion present; a trusted adult other than the parent whom the child would feel most comfortable with such as an adult sibling, aunt, uncle, cousin, or the person caring for the child. Such interviews will enable children and parents or caregivers to provide a personal narrative of their experiences, leading to thick description fitting with interpretive research (Moustakas, 1994; Sarantakos, 2005). Semi-structured interview guides (Appendices 11, 12, and 13) which are composed of open-ended questions will facilitate participants’ narratives (Cohen, Kahn, & Steeves, 2000; Durrheim, 2006; Riessman, 2008). All interviews will be transcribed verbatim. Interviews will take place in a confidential space at the Princess Margaret Cancer Centre, or Toronto General Hospital (site of Dr. Rodin’s research offices), or in participants’ homes. If a face-to-face interview with a parent or caregiver is not possible due to family circumstances, the interview will be conducted over the phone and digitally audio recorded. Interviews with children age 6-16 will not be completed over the phone.

The interview guides will be pilot tested for acceptability on two families (children and parents or caregivers). Following the pilot tests, the interview guides will be revised accordingly prior to completing the remaining interviews. If the revisions are minor, the data collected from the pilot testing will be included in the study. If significant revisions are required, the data will not be included as part of the analysis and further pilot testing will be conducted to ensure the revised interview guides are reflective of the study objectives. The qualitative interview guides are guides only and expected to evolve over the course of the study. Any revisions will remain reflective of the original study objectives and as such revisions will not be submitted for REB amendment approval.

Additional methods of data collection will involve an Illness Time Line (Appendix 14) which was developed by Gabrielle Pitt (2000) to document the chronological sequence of the parent’s illness and any aspects involving the children (for example, when the children were informed of the initial diagnosis and the parent’s cancer status). An Illness Time Line will also be completed by children to capture their sense of events concerning their parent’s cancer. A Worry Meter for Children (Appendix 16), also developed by Gabrielle Pitt (2000), will be completed by children to determine an understanding of the level of worry in relation to their parent’s illness.
parents living with cancer and the well parents or caregivers will complete a Parent or Caregiver Distress Rating Scale (Appendix 15). This rating scale was adapted from the Worry Meter for Children by Gabrielle Pitt (2013). It uses the same rating scale but allows for more detail in the responses from the adults. The Time Lines, Worry Meters, and Rating Scales may also provide a focus for discussion during interviews as indicated in the interview guides.

Field notes represent an additional method of data collection which will be completed contemporaneously by this doctoral student. These notes will encompass what this researcher hears, sees, experiences, and reflects on during the data collection process. In addition a reflective journal will be kept providing space for attention to this researcher’s subjectivity during the data collection process.

4.3 A description of the measures taken to minimize/avoid bias.
In qualitative research, minimizing or avoiding bias can be achieved through rigor; the authenticity of the findings and credibility of interpretations (Creswell, 2002). Trustworthiness is the most important facet in achieving rigor in qualitative research. Trustworthiness will be established through the six strategies for enhancing rigor as indicated by Padgett (1998): prolonged engagement; triangulation (theory and data); peer debriefing and support; negative case analysis; and an external audit.

Prolonged engagement is essential in establishing the researcher’s credibility in relation to an integrated knowledge of the research focus (Padgett, 1998). It is related to the duration of time spent by the researcher in the field of study. In addition to more than thirty years of experience working with children and families, this doctoral candidate (Gabrielle Pitt) has over thirteen years of experience directly related to oncology and palliative care, specifically working with children and families coping with end-stage cancer. Furthermore, this doctoral candidate will spend a minimum of three hours with each participating family conducting one hour interviews with each parent or caregiver and with the child (or children). This engagement will enable a strong connection with the respective families adding to the integrated knowledge.

Triangulation refers to the incorporation of diverse sources of data. As indicated previously, several sources of data will be used to ensure richness in the analysis and results. Another form of triangulation involves the use of a wide range of informants (Lincoln, 1995). As the interviews will involve ill parents, well parents or caregivers and children from a variety of diverse backgrounds, this will support triangulation of data.

With regard to peer debriefing and support, this proposed study will complement the three studies conducted by Dr. G. Rodin and his research team at the Princess Margaret Cancer Centre. As such, this doctoral candidate will have the opportunity to debrief with researchers at the Princess Margaret Cancer Centre. In addition the doctoral committee, in which each member holds expertise in areas directly related to this study (psychosocial oncology and palliative care, attachment, child and family, qualitative research and interpretive hermeneutic phenomenology) will provide expertise, debriefing and support.

Finally, an audit trail is achieved through comprehensive field notes, reflexive journal entries and a methodological account of all decisions made with the purpose of ensuring that another
Further to Padgett’s strategies, reflexivity, a process of self-awareness in the researcher, is an important dimension in establishing trustworthiness. “A consideration of self as a researcher, and self in relation to the topic of research, is a pre-condition for coping with bias” (Rajendran, 2001, p. 6). With phenomenology, van Manen referred to reflexivity as “hermeneutic alertness”, which occurs when researchers step back to reflect on the meanings of situations rather than accepting their pre-conceptions and interpretations at face value (1997, as cited in Ajjawi & Higgs, 2007, p. 622). To this end, this doctoral candidate’s reflexive journal will also provide space to document possible emotional responses that arise from the interviews. Fully incorporating each of these strategies outlined in this section will establish trustworthiness and rigor, in turn minimizing or avoiding bias in this qualitative study.

4.5 The expected duration of subject participation, and a description of the sequence and duration of all trial periods, including follow-up, if any.

The expected duration of participation for ill parents and well parents or caregivers is 1 ½ to 2 ½ hours. The total duration involves an initial meeting to determine eligibility and review, sign and witness the respective consent forms (approximately 30 to 60 minutes); time for completion of Demographic Information Forms, the Illness Time Line and the Parent or Caregiver Distress Rating Scale (approximately 15 to 30 minutes); and the actual interview (45 to 60 minutes). The consent and other forms can be completed during the initial eligibility meeting, or the parent or caregiver may take the forms home to complete and return by mail (a stamped return envelope will be provided).

The expected duration of participation for children is approximately 1 ¼ to 1 ½ hours; approximately 30 to 60 minutes to review, sign and witness the consent/assent form and approximately 45 to 60 minutes for the interview. The child will complete the Worry Meter in the interview.

If necessary, follow up during the data collection and analysis phases will take place by phone or in-person appointment to clarify information gained in an interview.

This doctoral candidate will follow up with each participant family by phone or mailed letter or card (Appendix 17) after the conclusion of the study, to thank them for their participation, and provide them with an overview of the results. In addition, if an ill parent dies during the course of the study, a condolence letter or card (Appendix 18) will be sent to participant family to acknowledge their loss.

4.6 The expected frequency and duration of study visits (anticipated time commitment) for study participants

Each participant parent or caregiver will be involved in one initial meeting to determine eligibility and review sign and witness the respective consent forms (approximately 30 to 60 minutes). Each participant family will be involved in three individual interviews (parent living with advanced cancer, well parent or caregiver, and child; each approximately 45 to 60 minutes in length). The number of interviews per family may increase dependent on the number of
additional children, six to eighteen years of age, who may also be interviewed based on purposive sampling. The consent and other forms can be completed during the initial eligibility meeting, or the parent or caregiver may take the forms home to complete and return by mail (a stamped return envelope will be provided).

In addition, parents or caregivers will be reimbursed for parking if requested.

4.7 A description of the "stopping rules" or "discontinuation criteria" for individual subjects, parts of trial and the entire trial.
Participation in this study is voluntary. Parents, caregivers or children may choose to not answer an interview question(s), and/or they may decide to leave the study at any time.

5.0 Selection of Subjects
5.1 Subject inclusion criteria.
   a) Patients diagnosed with advanced or life limiting cancer (broadly corresponding to an expected survival of less than 6 to 24 months);
   b) Well parents or caregivers;
   c) If one parent consents to participate in the study but the other parent or caregiver does not provide consent or is too ill to participate, the family will be included in the study
   d) Children six to eighteen years of age;
      i. As this proposed research captures children’s meaning making of the cancer of a parent, it is necessary that the children be aware of their parent’s cancer in order to be included in the study.
   e) All participants must be sufficiently fluent in English (both receptively and expressively) to answer the interview questions. In addition parents must have sufficient literacy in English to understand and complete the Information Forms, and the Informed Consent and Informed Assent Forms.

5.2 Subject exclusion criteria.
   a) Patients and well parents or caregivers and/or children that have limited skills in English (both receptively and expressively) representing barriers to providing informed consent/assent and/or understanding interview questions;
   b) Cognitive impairment in the patient, well parent or caregiver and/or child
   c) Children who do not provide their assent to participate in the study despite their parents providing consent.
   d) In a two parent household, or separated or divorced households where parents have shared custody/decision making, when one parent agrees to provide consent for a child (children) to participate but the other parent does not agree to provide consent.

5.3 Withdrawal of Subjects
5.3.1 Participants may be withdrawn from the study if
   a) They choose to withdraw
      i. If parents, caregivers or children decide to leave the study, the information provided and that was collected before the participant(s) withdraws from the study will be used in the study. No new information will be collected without the respective participant’s permission. Additionally a participant’s decision to withdraw from the study will in
b) Cognitive impairment is detected
   i. Physical deterioration in health leads to inability to complete interviews

c) Death

8.0 Assessment of Safety (if applicable)
8.1 Specification of safety parameters.
This study involves qualitative interviews and does not affect the patients’ care at the Princess Margaret Cancer Centre.

During an interview, if a parent, caregiver or child experiences emotional difficulty due to the nature of the questions or topics being discussed, he/she can choose not to answer any questions or the interview can be stopped. The parent, caregiver or child (children) can choose to continue the interview at that time, or another time that is convenient for the participant; or he/she can choose not to continue the interview at all.

A referral for psychosocial counselling services can be made if a parent, caregiver, and/or child experiences distress during or after the interviews and needs further support. Such services could be available for the patient and well parent through the Princess Margaret Cancer Centre Psychosocial Oncology and Palliative Care Program, or through regional mental health agencies, family services or licensed private practitioners. For children referrals can be made through regional children’s mental health agencies, family services, or licensed private practitioners.

If, as a result of answering questions in the interview, it is determined that a child is at risk of self-harm, or he/she has been harmed physically, emotionally or neglected, this study delegate, Gabrielle Pitt, must contact Children’s Aid Society as duty to report.

If suicidal intent is revealed by a participant, Dr. Gary Rodin will be contacted immediately by phone or pager, or if unavailable, the psychiatrist on call at POPC, for guidance and if necessary an emergency assessment.

9.0 Statistics
9.1 A description of the statistical methods to be employed, including timing of any planned interim analysis(ses).
Data analysis will be interpretive and on-going in nature looking for clusters of meaning, assumptions, patterns, and themes to develop a rich textual “restorying” true to the essence of the experiences of the participants (Cohen, Kahn, & Steeves, 2000; Riessman, 2008; Thomas, 2006). Reflective of the rich data collected in this phenomenological study, an inductive approach will utilized. This involves a process of layered reading, extracting statements, formulating meaning, clustering and validating themes, and synthesizing meanings and essences which will enable a piecing together of themes that emerge from the participants’ stories to form a comprehensive picture of the phenomenon (Mills, Bonner, & Francis, 2006; Thomas, 2006). Data for the children and parents or caregivers will be analyzed separately. Both individual themes of participants and collective themes that occur across the group of participants will be part of the analysis. An important step in the analysis of this qualitative research study pertains to
establishing trustworthiness, thereby enhancing rigor. Negative case analyses are important strategies in establishing trustworthiness (Padgett, 1998). The intent of this analysis is to gain a detailed understanding reflective of the essence of the complexities of parents’ advanced cancer as experienced by children and their parents or caregivers.

9.2 The number of subjects planned to be enrolled. In multicenter trials/studies, the numbers of enrolled subjects projected for each trial/ study site should be specified.
It is expected that 10 to 12 families (approximately 30-36 subjects) will participate in this study.

9.3. Reason for choice of sample size, including reflections on (or calculations of) the power of the trial/ study and clinical justification.
This sample size is appropriate for a phenomenological study with the goal of obtaining a varied, rich and deep understanding or essence of the participants’ experiences (Creswell, 2002; Kreuger & Neuman, 2005; Smith, & Osborn, 2007). It is important to note that the total sample size cannot be determined as it is essential to sample until saturation or redundancy of information is achieved. According to Strauss and Corbin, the benchmark for judging saturation is when “no additional data are being found whereby the researcher can develop properties of the categories (1998, p. 61).

9.6 The selection of subjects to be included in the analyses (e.g., all randomized subjects, all dosed subjects, all eligible subjects, evaluable subjects).
All subjects will be included in this qualitative analysis.

10.0 Direct Access to Source Data/Documents
A description of the parties allowed having direct access to the study related documents/ source data/documents, e.g. for monitoring, audits, REB review, or a regulatory inspection(s) etc. Gabrielle Pitt, PhD candidate and study delegate, and Dr. Gary Rodin, the study PI, will have direct access to all of the study related documents/source data. This candidate’s doctoral committee will be involved in discussions of the study as the interviews are being conducted, the results are being analyzed, and the dissertation is being reviewed. Therefore after the information has been protected and made anonymous/confidential, the committee members will have access to the study related data. In addition parties related to monitoring, audits, REB reviews and regulatory inspections will have direct access to documents related to the study in order to complete their respective functions.

11.0 Quality Control and Quality Assurance Procedures
A description of a Quality Control system for review of all source documents and laboratory results/reports to ensure accuracy and completeness.
The primary system of Quality Control is review with the doctoral committee and with the research team of Dr. Rodin at the Princess Margaret Cancer Centre. In addition, the Cancer Clinical Research Unit (CCRU) at the Princess Margaret will provide research guidance and training to the study delegate (G. Pitt) who will enter all participating study patients into the Clinical Research Record (CRR), part of the Electronic Patient Record (EPR).
12.0 Ethics
Description of ethical considerations relating to the trial.

12.1 Consent process (If waiver of consent is required sufficient justifications must be provided).

12.1.1 A description of how and by whom potential study participants will be identified.

In light of the nature of this study, participants meeting the inclusion criteria will be sought through the use of nonprobability purposive sampling to identify participants who are representative of relevant dimensions of the target population (Kreuger & Neuman, 2006). Dr. Gary Rodin (study PI) and his team at the Princess Margaret Cancer Centre are currently approaching patients with metastatic and advanced cancer for three studies at the Princess Margaret. These studies include: (1) UHN REB 12-5609-CE: A study of physical and psychological symptoms in patients with pancreatic and other gastrointestinal cancers (G. Rodin, PI; P. Fitzgerald, Co-I); (2) UHN REB 09-0855-C: A randomized controlled trial of a brief psychotherapy referred to as Managing Cancer and Living Meaningfully (CALM) for patients with metastatic cancer (G. Rodin, PI; S. Hales, Co-PI); and (3) UHN REB 12-0371-CE: A study of the experience of advanced cancer in young adults (G. Rodin, PI; M. Knox, Co-I).

A linkage between these studies for the purpose of identifying patients who meet the inclusion criteria for the present study (a parent with advanced cancer; a well parent or caregiver; child/children age 6-18 years; English-speaking) will be established and this information provided by Dr. Rodin’s study team to Gabrielle Pitt (PhD candidate) for possible recruitment to the present study. All patients who meet medical inclusion criteria for the three studies above will be medically eligible for the present study of patients with life-limiting cancer. Participants in the studies above are identified by research/nurse coordinators during their first assessment at Princess Margaret (Pancreatic Cancer study) or by a treating oncologist (Young Adult study), or by research staff using PHS clinic lists from the participating sites that are pre-screened for medical eligibility in the electronic patient record (EPR) (all three studies). To reduce potential burden, eligible patients will only be approached for recruitment to the present study either at the conclusion of the six month CALM trial, or following completion of the Young Adult study, or between three-monthly assessments or following completion of the longitudinal Pancreatic Cancer study, or following withdrawal from or refusal of any of the studies. Patients with families with children six to eighteen years of age will be identified to G. Pitt from the demographic and medical data of these studies, and she will use the contact information provided to contact patients and their families by mail with an introductory recruitment letter clearly outlining information about the study (Appendix 2), followed by a telephone call to describe the present study and discuss possible recruitment.

Further to the linked studies above representing potential sources of participant families, health professionals (oncologists, physicians, psychiatrists, psychologists, nurses, and social workers) working with patients diagnosed with advanced cancer at the Princess Margaret Cancer Centre will be consulted to identify families fitting the inclusion criteria. A recruitment letter outlining information about the study (Appendix 1) will be provided to medical oncologists and the staff in oncology clinics and in the Department of Psychosocial Oncology and Palliative Care (POPC) at the Princess Margaret Cancer Centre to assist with the identification of potentially eligible participants and their families. Health professionals provide a patient and their family with a copy of the introductory recruitment letter (Appendix 2) and the study delegate will follow up by
telephone to discuss possible recruitment; or, they will provide the study delegate with contact information (with the patient’s permission) and she will contact the patient and their family by mail with the introductory recruitment letter (Appendix 2), followed by a telephone call to describe the study and discuss possible recruitment.

12.1.2 A description of who will make initial contact with research participants regarding the study
An introductory recruitment letter clearly outlining information about the study (Appendix 2) will be provided to eligible patients by mail or by the research/nurse coordinator or treating oncologist/surgeon/clinic nurse or POPC staff. For patients who are identified as meeting the inclusion criteria but who cannot be reached at their respective clinic or POPC appointment, the oncology and/or POPC staff (with the patients’ consent) will provide this doctoral candidate (G. Pitt) with their contact information. This candidate will then contact eligible patients by telephone and this letter may be mailed to them.

12.1.3 A description of who will obtain informed consent from research participants.
Informed Consent for Parents
This doctoral candidate (G. Pitt) will review the parameters of the study with patients either in person following an appointment at their respective clinic or by telephone. Copies of the Informed Consent Form (Appendix 4) will be provided to, and reviewed with, patients who agree to participate in the study. Sufficient time will be provided to answer all questions, ensuring potential participants fully understand the study; as per the informed consent process. For those participants who agree to provide their consent to participate, the Informed Consent Form will be signed, witnessed and dated and a copy given to the participants for their records. This process of providing informed consent will also be conducted with patients’ partners or caregivers ensuring their full understanding of the parameters of the study and they will sign their own Informed Consent Form.

Patients and/or well parents or caregivers who are contacted by telephone and agree to participate will be invited to meet with this doctoral candidate at the Princess Margaret Cancer Centre to review the study and provide written consent (Telephone Recruitment Script, Appendix 3). For patients and/or well parents or caregivers who prefer to have the Informed Consent Form mailed to them, they will be asked to read, sign and date the form and return it with the questionnaires to the doctoral candidate using the stamped addressed envelope provided by the study.

Informed Consent for Children 17 to 18 years of age
According to the Research Ethics Board of Health Canada, children 17 to 18 years of age are considered “mature minors” and are eligible to consent to participate in research (Health Canada, 2010, p. 1). Therefore the process for gaining consent for patients and well parents/caregivers (described above) will be followed with children in this age group. An Informed Consent Form for Children 17 to 18 years of age will be reviewed with each participant who agrees to participate for them to sign and date (Appendix 5) and a copy of the consent form will be provided for their records.
12.1.4 Consent obtained from specific group

Assent for Children 6 to 16 years of age

Parents must provide their consent for the child (children) who are 6 to 16 years of age to participate however the child’s (children’s) assent to participate must also be gained. Patients and/or the well parents or caregivers will be made aware of the assent process as it relates to the children’s participation in the study and will be provided with a copy of the Information and Assent Form for Children (Appendix 6). As with the process for seeking informed consent for parents and for children 17 to 18 years of age, sufficient time will be provided to parents to ask questions ensuring they understand the study as it relates to the participation of their child (children). This doctoral candidate will then meet with the child (children) and the patient and/or parent or caregiver to discuss the parameters of the study. The Information and Assent Form for Children will be reviewed with the child (children) ensuring they too have sufficient time to ask questions and have their concerns answered. Once the child (children) fully understands the study and their participation, their assent will be sought verbally. Patients and well parents caregivers will be present when the study is being explained to the child (children). When the child (children) verbally assents to participating, the patient and/or parent or caregiver will be asked to read, sign and date the Information and Assent Form for Children. Copies of the signed, witnessed and dated assent form will be provided to parents.

If a child requests to have a companion, a trusted adult other than the parent whom the child would feel most comfortable with such as an adult sibling, aunt, uncle, cousin, or the person caring for the child, present in the interview, the identified companion will meet with this study delegate (G. Pitt) to discuss his/her role as a non-participating companion while the child is taking part in the interview, and to review the Informed Consent Form for Companions (Appendix 7) if the companion is someone other than a parent or caregiver already consented in this study. The process for obtaining informed consent for parents outlined previously in the protocol (Section 12.1.3) will be followed with companions.

Following the process of obtaining informed consent of patients and well parents or caregivers, and informed assent of children, all participants will be advised that they can contact this doctoral candidate (G. Pitt) at any time if they have further questions or concerns about the study. Copies of the signed witnessed and dated consent forms will be provided to all participants.

The process of obtaining informed consent / assent with each potential study participant will be documented by Gabrielle Pitt, the study delegate, in the Source Notes (Appendix 21).

12.2 A statement of review and approval of the study by the Research Ethics Board before any study related procedures commenced. A detailed study Ethics Protocol (this document) has been developed and ethics approval will be sought from the University Health Network Research Ethics Board. Following this approval and Institutional Approval from the University Health Network, administrative approval will be sought from the University of Toronto Health Sciences Research Ethics Board.
12.3. A statement of review and approval of any amendment to the study by the Research Ethics Board before any changes implemented beside these to eliminate immediate hazard to the study participants.

Although amendments are not anticipated, it is important to acknowledge there may be occasion to put forth an application of amendment(s) to the UHN REB, and the University of Toronto REB for approval.

13.0 Data Handling and Record Keeping

13.1. A description of the process for data recording to ensure accuracy, completeness, legibility, and timeliness of the data.

All interviews will be transcribed verbatim by the study delegate (Gabrielle Pitt), or if required, by WordWrap Associates Inc., a transcription company in Markham, Ontario (www.wordwrap.com). This company has an existing service provider agreement with Dr. G. Rodin, PI, and has also provided transcription services for other qualitative studies conducted by investigators in the Department of Psychosocial Oncology and Palliative Care at Princess Margaret. A copy of this service provider agreement will be appended to the CAPCR application.

13.2 A description of where the data will be recorded

Each participant will be provided with a unique identification (ID) number. These numbers will be used on all digital recording, transcriptions, and any documentation completed by children or parents. Participants’ names or any identifying information will not be used on any documents with the exception of the study recruitment Source Notes (Appendix 18). Personal identity or information will not be released or printed at any time.

Data will be recorded and stored according to UHN ‘Storage, Transport & Destruction of Confidential Information' policy: as electronic files on study-specific network drives, folders or intranet sites on a secure UHN network or, temporarily, on an encrypted biometric USB key or an encrypted computer or digital audio-recorder.

As indicated by the University Health Network, all paper data will be stored in at the Princess Margaret Cancer Centre or Toronto General Hospital (in the research offices of Dr. G. Rodin) (UHN premises) in a locked cabinet, container, and/or room, whose access is restricted to this doctoral candidate (G. Pitt) and Dr. Gary Rodin who will require the information to fulfill their roles in this study.

As this study does not involve a clinical trial all records and documents pertaining to the study will be retained by the study trial site at UHN for at least 10 years from the completion of the study after which time they will be destroyed. Once the interview transcriptions have been verified for accuracy and coding and analysis are complete, the audio-recordings will be destroyed.

13.3. An indication what will be considered source documents and source data.

All data collected in this study will be considered source data (Demographic Information Forms; Signed Information Consent/Assent Forms, Time Lines, and Worry Meters for Children, Parent or Caregiver Distress Rating Scales, and Transcripts).
13.4 An indication whether the data will be transcribed directly on to Case Report Forms. Data will not be transcribed directly on to Case Report Forms

**14.0 Financing and Insurance (if applicable):**
Financing and insurance if not addressed in a separate agreement.

**15.0 Publication Policy**
Publication policy, if not addressed in a separate agreement. Dissemination of results will involve presentations at oncology, palliative care and social work social work meetings, workshops or conferences. In addition, the results will form the basis of articles in peer-reviewed journals. Further to this the results of the interviews will also inform the development of developmentally appropriate supports for children and parents living with advanced cancer. Such supports will be presented to professionals such as social workers in addition to stakeholders such as cancer support agencies, hospices, and regional children’s mental health and family support agencies. Finally supportive interventions for patients and their partners/parents such as pamphlets and parent/child support groups will be created.

**16.0 Supplements**
Appendices

1. Recruitment Information Letter for Health Care Professionals
2. Introductory Recruitment Letter for Patients
3. Telephone Recruitment Script
4. Informed Consent Form for Parents
5. Informed Consent Form for Children 17 to 18 years of age
6. Information and Assent Form for Children 6 to 16 years of age
7. Informed Consent Form for Companions
8. Parent Living with Cancer Demographic Information Form
9. Well Parent or Caregiver Demographic Information Form
10. Child Demographic Information Form
11. Interview Guide – Well Parent or Caregiver
12. Interview Guide – Parent Living with Cancer
13. Interview Guide – Children
14. Illness Time Line
15. Parent or Caregiver Distress Rating Scale
16. Worry Meter for Children
17. Thank You Letter Template
18. Condolence Letter Template
19. Volunteer/Community Service Letter for Teenage Participants Template
20. Budget
21. Source Notes

**17.0 References** 24 - 27
17.0 References


Living with Uncertainty: Psychosocial Needs of Children Coping with a Parent’s Cancer


Date

Dear _______________________

We are writing to let you know about a research study called “Living with Uncertainty: Psychosocial Needs of Children Coping with a Parent's Cancer” taking place at the Princess Margaret Cancer Centre. This study is being conducted by Gabrielle Pitt, a PhD Candidate working with Dr. Gary Rodin, Head of the Department of Supportive Care, with the approval of your oncologist or oncology division and the Research Ethics Board at the hospital. This study is open to adults diagnosed with cancer who attend clinics at the Princess Margaret Cancer Centre. The study also focuses on the children (6 to 18 years of age) of the adults diagnosed with cancer and their well parents. In addition as the adult supporting the parent with cancer and child (children) may not be a parent, the study will also focus on alternate caregivers.

The purpose of this study is to develop an in-depth understanding of the experiences of children, their parents living with cancer, and their well parents or caregivers. What meaning do children make of the situation? How do you and your child (children) cope? What supports do you have to help your child (children)? What additional supports do you think you or your child (children) need? This study will give you and possibly your child (children) an opportunity to help us understand your situation. Finally this study will also provide information to help social workers and professionals who offer supports to children and parents coping with a parent living with cancer. If you agree to participate, you and/or your child’s well parent or caregiver will be asked to complete an interview with Gabrielle Pitt. In addition your child (children) will have the option to also complete an interview with Gabrielle Pitt. The questions that will be asked of you, your partner or caregiver, and possibly your children have been designed to be non-distressing and will help us to understand your situation.

If you have any questions about the study, please call the following number: 416-340-4800 (ext.7697). Gabrielle Pitt may contact you at your next clinic visit, or by telephone, to discuss the project further and to invite you to participate. If you choose not to participate after speaking with Gabrielle Pitt please know that your care at the Princess Margaret Cancer Centre will not be affected. If you decide to take part in the study, you can also stop your participation at any time.

Thank you for considering participation in this study.
Dr. Gary Rodin  
Principal Investigator  
Head, Department of Supportive Care  
Princess Margaret Cancer Centre  

Gabrielle Pitt, PhD Candidate  
Factor-Inwentash Faculty of Social Work  
Collaborative Program in Life Course and Aging  
University of Toronto
LIVING WITH UNCERTAINTY:
PSYCHOSOCIAL NEEDS OF CHILDREN COPING WITH A PARENT’S CANCER

TELEPHONE RECRUITMENT SCRIPT

If the Potential Participant Answers Phone …

Gabrielle Pitt, Doctoral Candidate:

[Greeting], may I speak to [Potential Participant’s Name], please?
Hello, my name is Gabrielle Pitt and I am a PhD Candidate working with Dr. Gary Rodin at the Princess Margaret Cancer Centre.

I am calling to follow up on a letter that you may have recently received [in clinic/by mail] inviting you to participate in a research study taking place at the Princess Margaret Cancer Centre. This study relates to adults who have been diagnosed with cancer and who attend clinics at the Princess Margaret Cancer Centre. The study also focuses on the children (6 to 18 years of age) of the adults diagnosed with cancer and their well parents. In addition as the adult supporting the parent with cancer and child (children) may not be a parent, the study will also focus on alternate caregivers. The aim of this study is to develop an in-depth understanding of the experiences of children, their parents living with cancer, and their well parents or caregivers.

If you, the well parent or caregiver, and your child (children) are interested in taking part in this study, each of you will participate in an interview with me. The interviews will take place separately; however your child (children) will be given the option of participating in his/her interview alone, or with a companion present – a trusted adult other than the parent whom your child would feel most comfortable with such as an adult sibling, aunt, uncle, cousin, or the person caring for the child. This person will act as a companion to your child while the interview is taking place, however this person will not participate in the interview. The actual interviews will take about 45 – 60 minutes and will be completed at Princess Margaret (or by telephone if we are unable to meet at Princess Margaret). I will ask you and the well parent or caregiver general questions and questions related to your cancer, and the ways you help your child (children) understand and cope with the situation. I will ask your child (children) about what it is like to have a parent who has cancer.

Does this sound like a study you might be interested in hearing more about and maybe participating in?

[If no, proceed to Refusal script below.]

If yes: Provide study details and commence Informed Consent Process. Refer to Informed Consent Form.

If you agree to participate in this study, you will be briefly interviewed by me to make sure that you are eligible for the study. You will then be asked to complete an Informed Consent Form which I will review in detail with you. In addition, if your child (children) is under the age of 16,
you will need to provide consent for him/her to participate. Your child (children) will also need to provide his/her assent (agreement) to participate. This involves completing an Information and Assent Form (very similar to your Informed Consent Form). Your child’s well parent or caregiver will also complete an Informed Consent Form.

Finally, as the parent living with cancer, you will be asked to complete a Demographic Information Form. A Demographic Information Form will also be completed by the well parent or caregiver, and a Child Demographic Information Form will be completed for your child. In addition, you and the well parent or caregiver will complete an Illness Time Line and a brief questionnaire, a Parent or Caregiver Distress Rating Scale. Your child (children) will also complete an Illness Time Line (with your help if they need it) and a Worry Meter. The forms, the time lines, and questionnaires will provide me with some general information about your cancer, and also about your child (children), and the well parent or caregiver.

Do you have any questions? [Answer any questions/concerns]
Would you like to participate in this study?

[If no, proceed to Refusal script.]

If yes:
Thank you. Will you be attending any appointments at Princess Margaret in the near future? If so, could we arrange a time to meet to make sure that you are eligible for the study? If you are eligible, then we can review the Informed Consent Form, and you can complete the Demographic Information Forms, Illness Time Lines, and Parent or Caregiver Distress Rating Scale at our meeting or take them home for your review to complete and provide me at an agreed upon date. In addition, I will provide a stamped return envelope if you would like to return them by mail.

If yes: Arrange date/time/location to consent and complete the forms. Provide contact information if necessary for patient to cancel/reschedule.

Thank you very much for your time.

If no upcoming appointments:
I am happy to mail two copies of the Informed Consent Form, together with the Demographic Information Forms, Illness Time Lines, and Parent or Caregiver Distress Rating Scale to you. One copy of the consent form is for you to keep for your records and the other is for our study records. Please read, sign and date both copies of the Informed Consent Form and return one copy to us with your completed forms in the postage-paid return envelope that will be provided. Once you receive the consent form in the mail, I would be happy to review the consent with you over the phone and answer any questions you may have.

Before I send you the study information, would you be agreeable to being briefly interviewed over the phone to make sure you are eligible for the study?
If no, proceed to **Refusal script** unless alternate arrangements can be made to consent patient.

If yes: discuss eligibility

If patient unfortunately does not meet eligibility for the study at this time, thank patient for their time.

If patient is eligible for study, confirm mailing address to send the forms, and arrange for an interview.

Thank you very much for your time.

If call goes to answering machine…

*[Greeting]*, this is a call for [Potential Participant’s Name]. My name is Gabrielle Pitt and I’m calling from the Princess Margaret Cancer Centre to follow-up on a letter that you may have received in the mail, offering you an invitation to participate in a research study. This study relates to adults who have been diagnosed with cancer and who attend clinics at the Princess Margaret Cancer Centre. The study also focuses on the children (6 to 18 years of age) of the adults diagnosed with cancer and their well parents. In addition as the adult supporting the parent with cancer and child (children) may not be a parent, the study will also focus on alternate caregivers. The aim of this study is to develop an in-depth understanding of the experiences of children, their parents living with cancer, and their well parents or caregivers.

I will try to reach you again in the next few days. If you would like more information about this study, or to let me know whether or not you are interested in this study, please feel free to contact me [repeat name] at: 416-340-4800 (ext. TBD).

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**Refusal Script: If person declines to participate in the study…**

Thank you for your time. I understand that you do not wish to participate in this study. However, I would like to ask your permission to document some basic information for research purposes. This is strictly voluntary. If you agree, this information will be used to compare individuals who did and did not participate in our study. This will inform us about how representative our findings are, and will help us to plan future research studies. Neither your name nor any identifying information will be recorded. Can I ask you a few questions to record this information (e.g., age; gender; cancer type; date of diagnosis)?

If no:
*[Document reason for refusal, if provided]*. No other information will be recorded. Thank you for your time.

If yes: *Proceed to record basic information and reason(s) for refusal in the Declined to Participate Source Notes*
LIVING WITH UNCERTAINTY:
PSYCHOSOCIAL NEEDS OF CHILDREN COPEING WITH A PARENT’S CANCER

INFORMED CONSENT FORM FOR PARENTS
(Parents Living with Cancer, and Well Parents or Caregivers)

Principal Investigator:
DR. GARY RODIN, Head, Department of Supportive Care
   Princess Margaret Cancer Centre, University Health Network
   416-946-4504

Study Delegate:
   GABRIELLE PITT, PhD Candidate, Factor-Inwentash Faculty of Social Work
   Collaborative Program in Life Course and Aging
   University of Toronto
   416-340-4800 (ext. 7697)

Thesis Supervisor
   DR. FAYE MISHNA, Dean, Factor-Inwentash Faculty of Social Work
   University of Toronto

INTRODUCTION
You, as a parent living with cancer, or a well parent or caregiver, and your child (children) are being asked to take part in a research study, Living with Uncertainty: Psychosocial Needs of Children Coping with a Parent’s Cancer. Please read this explanation about the study and its risks and benefits before you decide if you and your child (children) would like to take part. You should take as much time as you need to make your decision. You should ask Gabrielle Pitt, the study delegate, to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends, family, and family doctor. Participation in this study is voluntary.

If your child (children) is under seventeen years of age, you, as the parent, must provide consent for your child (children) to participate in this study. Once you do so, your child (children) must give assent to agree to take part in the study. Gabrielle Pitt will also review with you the assent form which she will go over with your child (children) to help them understand the study, why it is being completed, and what is being asked of them. Gabrielle Pitt will also make sure that she answers any questions your child (children) may have.
BACKGROUND AND PURPOSE:
Coping with a parent’s cancer can be a time of considerable uncertainty and confusion for those involved, especially the children of the family. The limited research conducted to date has increased the understanding of issues such as communication with children and the effects of caregiver burden on parenting. However, very little research has incorporated the voices of children six to eighteen years of age and their parents.

The purpose of this study is to develop an in-depth understanding of the experiences of children and parents (or caregivers) coping with cancer. What meaning do children make of the situation? How do you make meaning of it as the parent living with cancer or as the well parent (or caregiver) caring for you and your child (children)? How do you and your child (children) cope? What supports do you have to help your child (children)? What additional supports do you think you or your child (children) need?

This study will give you, as the parent living with cancer or as the well parent (or caregiver), and your child (children) an opportunity to help us understand your situation. Finally this study will also provide information to help social workers and professionals who offer supports to children and parents or caregivers coping with a parent living with cancer.

You are being asked to participate because you have cancer, you are a patient at the Princess Margaret Cancer Centre, and you are a parent; or you are the well parent (or caregiver) for the child (children). Your child (children) is also being asked to participate. Approximately ten to twelve families will participate in this study at the Princess Margaret Cancer Centre over one year.

STUDY DESIGN:
A qualitative research design will be best to understand the emotional needs of children and parents or caregivers coping with the complexities of cancer. Interviews with you, as the parent with cancer, or the well parent or caregiver, and your child (children) will be completed by Gabrielle Pitt. The interviews will take place separately; however your child (children) will be given the option of participating in their interview alone or with a companion present – a trusted adult (adult sibling, aunt, uncle, cousin, etc.). This person will act as a companion to your child while the interview is taking place, however this person will not participate in the interview. These interviews will enable you, as parents or caregivers, and your child (children) to tell us about your experiences.

PROCEDURE:
If you, the parent with cancer, or the well parent or caregiver, and your child (children) agree to participate in this study, each of you will participate in one interview with Gabrielle Pitt. The interviews will take about 45 – 60 minutes, and each interview will be audio-recorded. Gabrielle Pitt will ask you general questions and questions related to your cancer or ill parent’s cancer, and the ways you help your child (children) understand and cope with the situation. Your child (children) will be given the option of participating in their interview alone or with a parent/caregiver or adult sibling present during the interview. This person will act as a companion to your child while the interview is taking place, however this person will not participate in the interview.
In addition, prior to the interview you and your child (children) will complete Demographic Information Forms for you, as the parent or caregiver, and for the child (children), an Illness Time Line of events related to your cancer, and a Parent or Caregiver Distress Rating Scale. These forms will take approximately 15 to 30 minutes to complete. During the interview, your child (children) will also complete a Worry Meter, 1 – 10 scale, to help us understand your child’s worry about the situation. Finally all interviews will be audio-recorded and transcribed, or written up, for research purposes. By signing this consent form, you are acknowledging that the interview will be taped and that you agree to be audio-recorded. With your permission, your child (children) will provide their assent to be interviewed.

Approximately ten days before each interview, Gabrielle Pitt will phone you to arrange appointments for you, the parent with cancer and/or the well parent or caregiver and your child (children) that are at a convenient time for each of you. Gabrielle Pitt will attempt to schedule these appointments on the same day as your other appointments at the Princess Margaret Cancer Centre. Alternately if you and/or your child (children) prefer to be interviewed in your home or by telephone this can be accommodated.

**VOLUNTARY PARTICIPATION:**
Your participation, in addition to your child’s (children’s) participation in this study, is voluntary. You and/or your child (children) may decide not to be in this study, or to be in the study now and then change your mind later. You and your child (children) may leave the study at any time without affecting your care. You and/or your child (children) may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”.

**WITHDRAWAL FROM STUDY:**
If you and/or your child (children) decide to leave the study, the information you provided and that was collected before you left the study will still be used. No new information will be collected without your permission. Your decision to withdraw from the study will in no way affect the treatment of the parent with cancer at the Princess Margaret Cancer Centre.

**RISKS:**
**Risks of Questionnaires**
If you or your child (children), experience any difficulty emotionally due to the nature of the questions or topics being discussed in the interview, you can choose not to answer any questions or the interview can be stopped. You and/or your child (children) can choose to continue the interview at that time, or another time that is convenient for you; or you and/or your child can choose not to continue the interview at all. You and your child (children) can talk about your concerns with Gabrielle Pitt at any time. If you feel you or your child (children) need further support, a referral can be made on your behalf for counselling services. Such services could be available through your oncology clinic and from the Department of Supportive Care if you are the person living with cancer or the patient’s family member; or through regional mental health agencies, family services or licensed private practitioners if you are the well parent or caregiver, and/or your children.
If, as a result of answering questions in the interview, it is determined that your child is at risk of harm to him/herself, or because he/she has said that someone has hurt (physically or emotionally) or neglected him/her, Gabrielle Pitt will have to contact Children’s Aid Society as duty to report.

**BENEFITS:**
Although you and your child (children) may not receive direct benefit from being in this study, a potential benefit may lie in the fact that this study will enable you and your child’s voice to be heard. Often children are not given a chance to tell others how they feel, and what they need to help them with what is happening to their parent. The increased understanding of the meaning of the experience of children coping with a parent living with cancer, and of parents parenting while living with cancer, or parenting while caring for a parent with cancer and children represent potential benefits for future children and parents. Furthermore, families coping with illness of a parent find that available supports for the parents or children are lacking in the community. The information obtained from you and your child (children) about your experiences will contribute to improved services for children and families coping with a parent’s cancer.

In addition, the increased understanding gained from the voices of children and parents (or caregivers) also represent a potential benefit to the hospital. This knowledge will enhance the ability of oncology teams to better meet the needs of patients who are parents and who have been diagnosed with cancer.

If your child is a teenager, he or she will be provided with a volunteer/community service letter to recognize the time he/she volunteered to participate in the study (2 hours).

**CONFIDENTIALITY:**
If you agree to participate in this study, Gabrielle Pitt will look at your personal health information. Gabrielle Pitt will collect only the information needed for the study.

**What is personal health information?**
It is any information that could be used to identify the parent living with cancer being treated at the Princess Margaret Cancer Centre. It includes the person’s name, address, and date of birth. It also includes diagnosis, and treatment received.

**How will the information be protected?**
As with all information collected for the study, it will be kept in a locked and secure area at University Health Network, or on secured University Health Network computer servers. A list linking the participants’ study numbers with their names will be kept by the study team in a secure place, separate from the participants’ study files. The information will be kept for 10 years after the study is completed, after which it will be destroyed. Audio-recordings, prior to transcription and verification, will be stored on secured University Health Network computer servers or encrypted and password protected devices that, when not in use, will be stored in a locked and secure area. After the transcripts have been verified for accuracy and data coding and analysis are complete, the audio-recordings will be destroyed.
Representatives of the University Health Network Research Ethics Board may look at the study records. This will include your personal health information. They may want to check that the information collected for the study is correct, and to make sure the study follows proper laws and guidelines.

All information collected during this study, including your personal health information, will be kept confidential. It will not be shared with anyone outside the study unless required by law. Excerpts, or passages, from the interviews may be used in presentations and reports. Your name, or any other detail that may reveal your identity, will not appear on the transcription of the interviews or in any published excerpts, reports, presentations or publications that may come from this study.

COSTS:
There will be no cost to you for taking part in this study. You will be reimbursed for parking if requested by you.

YOUR RIGHTS AS A PARTICIPANT:
If you decide to leave the study, the information you provided and that was collected before you left the study will still be used. No new information will be collected without your permission. Remember, you can refuse to take part or choose to leave the study at any time. This decision will in no way affect the treatment the parent with cancer is receiving at the Princess Margaret Cancer Centre.

Signing this consent form does not waive your legal rights. It does not relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities. You do not give up any of your legal rights by signing this consent form.

QUESTIONS ABOUT THE STUDY:
If you have any questions, concerns or would like to speak to the study team for any reason, please call: Gabrielle Pitt at 416-340-4800 (ext. 7697) or Dr. Gary Rodin at 416-946-4504.
If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.
CONSENT:
This study and the Informed Consent Form have been explained to me. I have been given the opportunity to ask questions. My questions have been answered. I have been assured that all information gathered will remain confidential. My name will not appear on any forms or publications. I further understand that if the study is not undertaken, or if it is discontinued at any time, the quality of my medical care, or the medical care of the parent living with cancer, will not be affected. I understand that I will be informed if any knowledge gained from this study could influence my decision to continue in this study. I know that I may leave the study at any time. I agree to take part in this study.

_________________________________  ____________________  _____________
Print Study Participant’s Name       Signature            Date
(You will be given a signed copy of this consent form.)

My signature means that I have explained the study to the participant named above. I have answered all questions.

__________________________________  ____________________  _____________
Print Name of Person Reviewing Study Signature            Date
Gabrielle Pitt, PhD Candidate
Factor-Inwentash Faculty of Social Work
Collaborative Program in Life Course and Aging
University of Toronto
INTRODUCTION
You and your parents (or caregiver) are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. You can ask me to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends, family, and family doctor. Participation in this study is voluntary.

BACKGROUND AND PURPOSE:
Why am I doing this study?
I am doing this study to learn more about children when one of their parents has cancer. I would like to answer questions like: What do you think about it? How does it make you feel? Who helps you understand what is happening with your parent? What else do you need to help you understand? This study will give you a chance to help me understand your situation. This study will also help people like me develop ways to provide support for children who also have a parent who has cancer. Approximately ten to twelve families will participate in this study at the Princess Margaret Cancer Centre over one year.
PROCEDURE:
What do you have to do if you take part in this study?
If you agree to take part in this study, you will talk with me about your situation and I will audio-record our conversation. By making an audio-recording I will have a record of what you told me which will help me with my research. Your parent(s) (or caregiver) will also meet with me at another time. When you and I meet I will ask you questions about what it is like to have a parent who has cancer. If you do not want to answer any of the questions, let me know and we can go to the next question. Before you come to meet with me, you can complete an Illness Time Line. I will be asking your parent(s) (or caregiver) to complete one also. When you come to meet with me you can bring it so we can talk about it. You will also complete a Worry Meter during the interview.

How long will I have to talk with you and where will we meet?
You and I will meet for up to an hour or as long as you feel you can. The meeting will take place where you and your parent feel it would be more comfortable. We can meet in a quiet room at the Princess Margaret Cancer Centre or in your home or we can talk by telephone if we are unable to meet in person. Finally our interview will be audio-recorded and transcribed, or written up, for research purposes. By signing this consent form, you are saying that you understand the interview will be taped and that you agree to be audio-recorded.

VOLUNTARY PARTICIPATION / WITHDRAWAL FROM STUDY:
Can I decide if I want to take part in this study?
Taking part in this study is totally up to you, it is voluntary. You may choose not to take part or to stop at any time. If you don’t want to take part in the study, you can tell your parents.

RISKS:
What may be difficult if I take part in this study?
If you get upset at any time while we are talking, we can stop. You can choose to continue talking after we take a break or we can meet again another time, or not at all. Also if you want to talk to someone who works with children about what is happening with your parent, we can tell your parents and I will help them find someone to help you.

BENEFITS:
What will be good if I take part in the study?
You may not receive any personal benefit from taking part in this study. Children who have a parent with cancer sometimes find that people don’t understand what they are going through, or what they need to help them with the situation. If you take part in this study your story will help people like me help children like you and their parents cope with what is going on. You can help make it better for other children and their parents.
CONFIDENTIALITY:
Will anyone know if I take part in this study or what I do?
No one other than your parent(s) (or the person taking care of you) will know that you took part in this study. I will make sure that whatever you tell me, your time line and worry meter are confidential. I will take notes and I will record what we talk about because it will help me remember what we said. I will not put your name on any paper so no one will know who you are. All the information from my meeting with you will be kept in a locked and secure area at University Health Network, or on special secured University Health Network computer servers which will be protected by a password. A list linking the participants’ study numbers with their names will be kept by the study team in a secure place, separate from the participants’ study files. The information will be kept for 10 years after the study is completed, after which it will be destroyed. After the interview transcripts have been checked for accuracy and the analyses are complete, the audio-recordings will be destroyed.

Representatives of the University Health Network Research Ethics Board may look at the study records to check that the information collected for the study is correct, and to make sure the study follows proper laws and guidelines.

All information collected during this study, including your parent’s personal health information, will be kept confidential. It will not be shared with anyone outside the study unless required by law. Excerpts, or passages, from the interviews may be used in presentations and reports. Your name, or any other detail that may reveal who you are, will not appear on the transcription of the interviews or in any published excerpts, reports, presentations or publications that may come from this study.

YOUR RIGHTS AS A STUDY PARTICIPANT:
If you decide to leave the study, the information you provided and that was collected before you left the study will still be used. No new information will be collected without your permission. Remember, you can refuse to take part or choose to leave the study at any time. This decision will in no way affect your parent’s care at the Princess Margaret Cancer Centre.

CONTACT INFORMATION:
Who do I talk to if I have any questions or concerns?
If you have any questions about the study or what you will be doing, you can ask me. You can also ask your parent to call me, Gabrielle Pitt, at 416-340-4800 (ext. 7697) or Dr. Gary Rodin at 416-946-4504.

Authorized Consent on Following Page
CONSENT FOR CHILD 17 TO 18 YEARS:
This study and the consent form have been explained to me. I have been given the opportunity to ask questions. My questions have been answered. I have been assured that all information gathered will remain confidential. My name will not appear on any forms or publications. I further understand that if the study is not undertaken, or if it is discontinued at any time, the quality of my parent’s medical care at the Princess Margaret Cancer Centre will not be affected. I understand that I will be informed if any knowledge gained from this study could influence my decision to continue in this study. I know that I may leave the study at any time. I agree to take part in this study.

_________________________________  ____________________  __________________
Print Study Child’s Name            Signature              Date

(You will be given a signed copy of this consent form.)

My signature means that I have explained the study to the participant named above. I have answered all questions.

_________________________________  ____________________  __________________
Print Name of Person Reviewing Study Signature              Date

Gabrielle Pitt, PhD Candidate
Factor-Inwentash Faculty of Social Work
Collaborative Program in Life Course and Aging
University of Toronto
LIVING WITH UNCERTAINTY:
PSYCHOSOCIAL NEEDS OF CHILDREN COPING WITH A PARENT’S CANCER

INFORMATION AND ASSENT FORM FOR CHILDREN
(6 to 16 years of age)

Principal Investigator:
DR. GARY RODIN, Head, Department of Supportive Care
- Princess Margaret Cancer Centre, University Health Network
  416-946-4504

Study Delegate:
- GABRIELLE PITT, PhD Candidate, Factor-Inwentash Faculty of Social Work
  Collaborative Program in Life Course and Aging
  University of Toronto
  416-340-4800 (ext. 7697)

Thesis Supervisor
- DR. FAYE MISHNA, Dean, Factor-Inwentash Faculty of Social Work
  University of Toronto

INTRODUCTION
Your parent(s) (or someone who is taking care of you) have allowed me to talk to you about a
research study that I am working on. I am going to spend some time telling you about the study
to help you understand why I am doing it, and what will take place. I will make sure that you
understand what you are going to be doing.

You can ask me questions about any part of this study which you do not understand. I will make
sure that all of your questions have been answered so you fully understand what you will be
doing. Then I am going to ask you if you are interested in taking part in the study

As you are a child, your parent must provide consent or agree for you to take part in this study. I
have showed this form to your parent so your parent understands what you will be doing.
BACKGROUND AND PURPOSE:
Why am I doing this study?
I am doing this study to learn more about children when one of their parents has cancer. I would like to ask questions like: What do you think about it? How does it make you feel? Who helps you understand what is happening with your parent? What else do you need to help you understand? This study will give you a chance to help me understand your situation. This study will also help people like me make supports for children who also have a parent who has cancer.

PROCEDURE:
What do you have to do if you take part in this study?
If you agree to take part in this study, you will talk with me about your situation and I will audio-record our conversation. By making an audio-recording I will have a record of what you told me which will help me with my research. Your parent(s) (or the person who is taking care of you) will also meet with me at another time. When you and I meet I will ask you questions about what it is like to have a parent who has cancer. If you don’t understand a question, let me know and I will ask it a different way. In addition, if you do not want to answer any of the questions, let me know and we can go to the next question. You can choose to meet with me on your own, or you can have someone there with you – an adult you trust such as an adult sibling, aunt, uncle, or cousin. This person will not participate in the interview. Before you come to meet with me, you can complete something I call an Illness Time Line. I will be asking your parent(s) to complete one also. You can do this time line with your parent(s) (or the person taking care of you), or you can do it on your own. When you come to meet with me you can bring it so we can talk about it. You will also complete a Worry Meter. Finally the audio-recording of our interview will be transcribed, or written up, for research purposes. By signing this assent form, you are saying that you understand the interview will be taped and that you agree to be audio-recorded.

How long will I have to talk with you and where will we meet?
You and I will meet for one hour or as long as you feel you can. The meeting will take place where you and your parent(s) (or the person taking care of you) feels it would be most comfortable. We can meet in a quiet room at the Princess Margaret Cancer Centre or in your home.

VOLUNTARY PARTICIPATION / WITHDRAWAL FROM STUDY:
Can I decide if I want to take part in this study?
Taking part in this study is totally up to you, it is voluntary. You may choose not to take part or to stop at any time or not answer any questions you do not want to answer. If you don’t want to take part in the study, you can tell your parent(s) (or the person taking care of you).

RISKS:
What may be difficult if I take part in this study?
If you get upset at any time while we are talking, we can stop. You can choose to continue talking after we take a break or we can meet again another time, or not at all. Also if you want to talk to someone who works with children about what is happening with your parent, we can tell your parent(s) (or the person taking care of you) and I will help them find someone to help you.
BENEFITS:
What will be good if I take part in the study?
Taking part in this study may not directly benefit you. However, children who have a parent with cancer sometimes find that people don’t understand what they are going through, or what they need to help them with the situation. If you take part in this study your story will help people like me help children like you and their parents cope with what is going on. You can help make it better for other children and their parents.

CONFIDENTIALITY:
Will anyone know if I take part in this study or what I do?
No one other than your parent(s) (or the person taking care of you) will know that you took part in this study. I will make sure that whatever you tell me, your time line and worry meter are confidential. I will take notes and I will record what we talk about because it will help me remember what we said. I will not put your name on any paper so no one will know who you are. All the information from my meeting with you will be kept in a locked and secure area at University Health Network, or on special secured University Health Network computer servers which will be protected by a password. A list linking the participants’ study numbers with their names will be kept by the study team in a secure place, separate from the participants’ study files. The information will be kept for 10 years after the study is completed, after which it will be destroyed. The transcripts of the interviews will checked for accuracy and once the analyses are complete, the audio-recordings will be destroyed.

CONTACT INFORMATION:
Who do I talk to if I have any questions or concerns?
If you have any questions about the study or what you will be doing, you can ask me. You can also ask your parent to call me, Gabrielle Pitt, at 416-340-4800 (ext. 7697) or Dr. Gary Rodin at 416-946-4504.

Parent’s Consent /Children’s Assent Authorization on Following Page
Child’s Assent
I was present when the researcher read this form aloud to my child. My child’s questions were answered. My child and I have been assured that all information gathered will remain confidential. My child knows that he/she may leave the study at any time. My child gave his/her verbal assent to take part in this study.

My child has requested to complete the interview on his/her own.
1) Yes  r  2) No  r

My child has requested to have another person present while he/she is being interviewed.
1) Yes  r  2) No  r

Name of person: __________________________________________________________

Relationship to the child:
The person accompanying the child in the interview has reviewed and signed an Informed Consent Form for Companions if he/she is someone other than a parent or caregiver already participating in this study.

(You will be given a signed copy of this assent form.)

My signature means that I have explained the study to the participant named above. I have answered all questions.

__________________________________________________________
Print Child’s Name

__________________________________________________________
Print Parent’s Name  Parent’s Signature  Date

Print Name of Person Reviewing Study  Signature  Date

Gabrielle Pitt, PhD Candidate
Factor-Inwentash Faculty of Social Work
Collaborative Program in Life Course and Aging
University of Toronto
LIVING WITH UNCERTAINTY:
PSYCHOSOCIAL NEEDS OF CHILDREN COPING WITH A PARENT’S CANCER

INFORMED CONSENT FORM FOR COMPANIONS
(Accompanying the Child in the Interview)

Principal Investigator:
DR. GARY RODIN, Head, Department of Supportive Care
- Princess Margaret Cancer Centre, University Health Network
  416-946-4504

Study Delegate:
- GABRIELLE PITT, PhD Candidate, Factor-Inwentash Faculty of Social Work
  Collaborative Program in Life Course and Aging
  University of Toronto
  416-340-4800 (ext. 7697)

Thesis Supervisor
- DR. FAYE MISHNA, Dean, Factor-Inwentash Faculty of Social Work
  University of Toronto

INTRODUCTION
You are being asked to take part in a research study as a companion of a child who is taking part in a research study, Living with Uncertainty: Psychosocial Needs of Children Coping with a Parent’s Cancer. As a companion you will be with the child in the interview room, however you will not take part directly in the interview with the child. Your role is to provide support to the child while the interview is taking place.

Please read this explanation about the study and its risks and benefits before you decide if you would like to take part as a companion for the child taking part in the study. You should take as much time as you need to make your decision. You should ask Gabrielle Pitt, the study delegate, to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends, family, and family doctor. Participation in this study is voluntary.

BACKGROUND AND PURPOSE:
Coping with a parent’s cancer can be a time of considerable uncertainty and confusion for those involved, especially the children of the family. The limited research conducted to date has increased the understanding of issues such as communication with children and the effects of
Living with Uncertainty: Companions’ Consent

caregiver burden on parenting. However, very little research has incorporated the voices of children six to eighteen years of age and their parents.

The purpose of this study is to develop an in-depth understanding of the experiences of children and parents or caregivers coping with cancer. What meaning do children make of the situation? How do parent living with cancer or as the well parent (or caregiver) caring for the ill parent and the child (children)? How do the parent and the child (children) cope? What supports do the parents have to help the child (children)? What additional supports do the parents think they, or their child (children), needs?

This study will give the parent living with cancer and/or the well parent or caregiver, and the child (children) an opportunity to help us understand their situation. Finally this study will also provide information to help social workers and professionals who offer supports to children and parents or caregivers coping with a parent living with cancer. Approximately ten to twelve families will participate in this study at the Princess Margaret Cancer Centre over one year.

You are being asked to participate because the child being interviewed has requested your presence in the interview to provide him/her with support. You will not be asked any questions, and you will not directly participate in the interview.

STUDY DESIGN:
A qualitative research design will be best to understand the emotional needs of children and parents (or caregivers) coping with the complexities of cancer. Interviews with the parent with cancer, or the well parent (or caregiver), and the child (children) will be completed by Gabrielle Pitt. The interviews will take place separately; however the child (children) will be given the option of participating in their interview alone or with a companion – a parent/caregiver or adult sibling. This person will act as a companion to the child while the interview is taking place, however this person will not participate in the interview. These interviews will enable parents (or caregivers), and the child (children) to tell us about their experiences.

PROCEDURE:
If the parent with cancer, or the well parent or caregiver, and the child (children) agree to participate in this study, each of them will participate in one interview with Gabrielle Pitt. The interviews will take about 45 – 60 minutes, and each interview will be audio-recorded. Gabrielle Pitt will ask them general questions and questions related to the cancer or ill parent’s cancer, and the ways they help their child (children) understand and cope with the situation. The child (children) will be given the option of participating in their interview alone or with a parent or caregiver or adult sibling present during the interview. This person will act as a companion to the child while the interview is taking place, however this person will not participate in the interview. In addition prior to the interview the parent living with cancer, the well parent or caregiver, and the child (children) will complete an Illness Time Line of events related to the parent’s cancer. During the interview, the child (children) will complete a Worry Meter, 1 – 10 scale, to help us understand the child’s worry about the situation. Parents (or caregivers) will complete a Distress Rating Scale. Finally all interviews will be audio-recorded and transcribed, or written up, for research purposes. By signing this consent form, you are acknowledging that
the interview with the child you are accompanying will be taped. With the parent’s permission, the child (children) will provide their assent to be interviewed.

Approximately ten days before each interview, Gabrielle Pitt will phone the parent or caregiver to arrange appointments for the parent with cancer and/or the well parent or caregiver and the child (children) that are at a convenient time for each of them. Gabrielle Pitt will attempt to schedule these appointments on the same day as the parent’s other appointments at the Princess Margaret Cancer Centre. Alternately if the parent or caregiver and/or the child (children) prefer to be interviewed in their home this can be accommodated.

**VOLUNTARY PARTICIPATION:**
Your participation in this study, in addition to the participation of the parent, caregiver and the child (children), is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting the treatment and care of the parent who has cancer.

**WITHDRAWAL FROM STUDY:**
If you or the parents, caregiver or the child (children) decide to leave the study, the information provided and that was collected before you left the study will still be used. No new information will be collected without your permission. Your decision to withdraw from the study will in no way affect the treatment of the parent with cancer at the Princess Margaret Cancer Centre.

**RISKS:**

**Risks of Questionnaires**
If the child (children) experiences any difficulty emotionally due to the nature of the questions or topics being discussed in the interview, the child can choose not to answer any questions or the interview can be stopped. You and or the child (children) can choose to continue the interview at that time, or another time that is convenient; or you and the child can choose not to continue the interview at all. You and the child (children) can talk about any concerns with Gabrielle Pitt at any time. If you (as the companion) feel you need further support regarding this situation, a referral can be made on your behalf for counselling services. Such services could be available through regional mental health agencies, family services or licensed private practitioners. If the child needs further support, Gabrielle Pitt can talk with the parents or caregiver about making a referral for counselling through regional children’s mental health agencies or licensed private practitioners.

If, as a result of answering questions in the interview, it is determined that the child is at risk of harm to him/herself, or because he/she has said that someone has hurt (physically or emotionally) or neglected him/her, Gabrielle Pitt will have to contact Children’s Aid Society as duty to report.

**BENEFITS:**
Although the parents or caregiver and the child (children) may not receive direct benefit from being in this study, a potential benefit may lie in the fact that this study will enable their voices to be heard. Often children are not given a chance to tell others how they feel, and what they need to help them with what is happening to their parent. The increased understanding of the meaning
of the experience of children coping with a parent living with cancer, and of parents parenting while living with cancer, or parenting while caring for a parent with cancer and children represent potential benefits for future children and parents. Furthermore, families coping with advanced illness of a parent find that available supports for the parents or children are lacking in the community. The information obtained from parents, caregivers and children about their experiences will contribute to improved services for children and families coping with a partner’s cancer.

In addition, the increased understanding gained from the voices of children and parents (or caregivers) also represent a potential benefit to the hospital. This knowledge will enhance the ability of oncology teams to better meet the needs of patients who are parents and who have been diagnosed with cancer.

CONFIDENTIALITY:
If you agree to participate in this study, Gabrielle Pitt will collect only the information needed for the study.

What is personal health information?
It is any information that could be used to identify the parent living with cancer being treated at the Princess Margaret Cancer Centre. It includes the person’s name, address, and date of birth. It also includes the diagnosis, and treatment received.

How will the information be protected?
As with all information collected for the study, it will be kept in a locked and secure area at University Health Network, or on secured University Health Network computer servers. A list linking the participants’ study numbers with their names will be kept by the study team in a secure place, separate from the participants’ study files. The information will be kept for 10 years after the study is completed, after which it will be destroyed. Audio-recordings, prior to transcription and verification, will be stored on secured University Health Network computer servers or encrypted and password protected devices that, when not in use, will be stored in a locked and secure area. After the transcripts have been verified for accuracy and data coding and analysis are complete, the audio-recordings will be destroyed.

Representatives of the University Health Network Research Ethics Board may look at the study records. This will include personal health information. They may want to check that the information collected for the study is correct, and to make sure the study follows proper laws and guidelines.

All information collected during this study, including personal health information, will be kept confidential. It will not be shared with anyone outside the study unless required by law. Excerpts, or passages, from the interviews may be used in presentations and reports. Names, or any other detail that may reveal identity, will not appear on the transcription of the interviews or in any published excerpts, reports, presentations or publications that may come from this study.
COSTS:
There will be no cost to you for taking part in this study. You will be reimbursed for parking if requested by you.

YOUR RIGHTS AS A PARTICIPANT:
If you decide to leave the study, the information you provided and that was collected before you left the study will still be used. No new information will be collected without your permission. Remember, you can refuse to take part or choose to leave the study at any time. This decision will in no way affect the treatment the parent with cancer is receiving at the Princess Margaret Cancer Centre.

Signing this consent form does not waive your legal rights. It does not relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities. You do not give up any of your legal rights by signing this consent form.

QUESTIONS ABOUT THE STUDY:
If you have any questions, concerns or would like to speak to the study team for any reason, please call: Gabrielle Pitt at 416-340-4800 (ext. 7697) or Dr. Gary Rodin at 416-946-4504. If you have any questions about your rights as a companion or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

Authorized Consent on Following Page
CONSENT:
This study and the Informed Consent Form for Companions have been explained to me. I have been given the opportunity to ask questions. My questions have been answered. I fully understand that my role will be to accompany the child in the interview; however I will not directly participate in the interview at all. I have been assured that all information gathered will remain confidential. My name will not appear on any forms or publications. I further understand that if the study is not undertaken, or if it is discontinued at any time, the quality of medical care the person with cancer will not be affected. I understand that I will be informed if any knowledge gained from this study could influence my decision to continue in this study. I know that I may leave the study at any time. I agree to take part in this study as a companion to the child who is participating in the study.

________________________________________  __________________________  ______________
Print Companion’s Name                     Signature                      Date

(You will be given a signed copy of this consent form.)

My signature means that I have explained the study to the companion named above. I have answered all questions.

________________________________________  __________________________  ______________
Print Name of Person Reviewing Study          Signature                      Date

Gabrielle Pitt, PhD Candidate
Factor-Inwentash Faculty of Social Work
Collaborative Program in Life Course and Aging
University of Toronto

Version: 06-November-2015
LIVING WITH UNCERTAINTY: 
PSYCHOSOCIAL NEEDS OF CHILDREN COPING WITH A PARENT’S CANCER

PARENT LIVING WITH CANCER DEMOGRAPHIC INFORMATION FORM

Please provide the appropriate information or check the appropriate box below. This information will be kept strictly confidential.

1. Age: ____________

2. Relationship with the child (children) participating in the study

    r 1) Mother  
    r 2) Father  
    r 3) Other (please specify) __________________________

3. Your current relationship status

    r 1) Single  
    r 2) Married  
    r 3) Common Law  
    r 4) Separated / Divorced

    r 5) Widowed

4. Relationship to other parent or caregiver participating in this study

    r 1) Married  
    r 2) Common Law  
    r 3) Separated / Divorced

    r 4) Relative (please specify): ___________________________________________________________________

5. When were you diagnosed with cancer? __________________________________________

6. What was the primary diagnosis? _______________________________________________

7. Has the cancer spread? If so where? _____________________________________________

8. What types of treatment have you received? (check as many as apply)

    r 1) Surgery  
    r 2) Chemotherapy  
    r 3) Radiation

    r 4) Other (please specify) ___________________________________________________
9. Are you receiving palliative care services?
   r 1) Yes   r 2) No

10. Are you receiving care in the Psychosocial Oncology Department at Princess Margaret?
    r 1) Yes   r 2) No

11. What health care providers are involved in your care? (check as many as apply)
    r 1) Family Physician   r 2) Oncologist   r 3) Palliative Care Physician
    r 4) Palliative Care Nurse   r 5) Social Worker   r 6) Psychiatrist / Psychologist
    r 7) Other Specialists (please specify) __________________________________________

12. Have you used, or are you currently using, any services in the community?
    r 1) Canadian Cancer Society
    r 2) Community support agencies for individuals living with cancer
        Please specify __________________________________________________________
    r 3) Private social worker, therapist, or psychologist
    r 4) Family support services
    r 5) Other (please specify) _________________________________________________
Additional Comments
Please use this space if there is any additional information which you feel would be helpful for me to know:
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
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LIVING WITH UNCERTAINTY: 
PSYCHOSOCIAL NEEDS OF CHILDREN COPING WITH A PARENT’S CANCER

WELL PARENT OR CAREGIVER DEMOGRAPHIC INFORMATION FORM

Please provide the appropriate information or check the appropriate box below. This information will be kept strictly confidential.

1. Age: ______________

2. Relationship with the child (children) participating in the study
   - 1) Mother
   - 2) Father
   - 3) Other (please specify) _______________________

3. Your current relationship status
   - 1) Single
   - 2) Married
   - 3) Common Law
   - 4) Separated / Divorced
   - 5) Widowed

4. Relationship to parent diagnosed with cancer who is participating in this study
   - 1) Married
   - 2) Common Law
   - 3) Separated / Divorced
   - 4) Relative (please specify): ___________________________________________________________________

5. How many hours a week do you spend caring for the parent with cancer? _______________

6. With regard to the child (children) participating in this study, how many hours a week do you spend parenting or caring for this child (these children)? _______________

7. Do you have family members or friends helping you with the care of the parent with cancer and with care of the child (children)?
   - 1) Yes
   - 2) No
   If you indicated yes, please specify? __________________________________________
8. What other supports do you have in your home to help care for the parent with cancer?
   r 1) Personal Support Worker  r 2) Health Care Aide  r 3) Nurse
   r 4) Other (please specify) ____________________________________________

9. What other supports do you have to help care for your child (children), or the child (children) you are caring for?
   r 1) Relative  r 2) Babysitter  r 3) Child Care
   r 4) Other (please specify) ____________________________________________

11. Have you used, or are you currently using, any services in the community for yourself?
    r 1) Canadian Cancer Society
    r 2) Community support agencies for individuals caring for persons living with cancer
       Please specify ______________________________________________________
    r 3) Private social worker, therapist, or psychologist (please specify) ______
    r 4) Family support services (please specify) ______________________________
    r 5) Other (please specify) _____________________________________________
Additional Comments

Please use this space if there is any additional information which you feel would be helpful for me to know:

______________________________________________________________________________
______________________________________________________________________________
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LIVING WITH UNCERTAINTY:  
PSYCHOSOCIAL NEEDS OF CHILDREN COPING WITH A PARENT’S CANCER  

CHILD DEMOGRAPHIC INFORMATION FORM  
(Regarding the Child Being Interviewed) 

Please provide the appropriate information or check the appropriate box below.  
This information will be kept strictly confidential. 

1. Age of child: ______________

2. Relationship with the child participating in this study  
   1) Mother  2) Father  3) Relative (please specify): ___________________________________________

3. Other children living in the home with this child:  
   1) Gender______ Age______  
   2) Gender______ Age______  
   3) Gender______ Age______  
   4) Gender______ Age______

4. Child’s Grade: ______________

5. Describe this child’s general mood:  
   1) Very happy  2) Happy  3) Worried  4) Sad  5) Angry

6. How well do you feel this child understands the situation with his/her parent?  
   1) Well  2) Confused  3) Not well  4) Does not want to know
7. Have you used, or are you currently using, any services in the community for this child?

r 1) Family physician

r 2) Community support agencies for children living with a family member with cancer
   Please specify __________________________________________________________

r 3) Children’s mental health agency
   Please specify __________________________________________________________

r 4) Teacher of school social worker ___________________________________________

r 5) Private social worker, therapist, or psychologist (please specify) ____________

r 6) Family support services (please specify) _________________________________

r 7) Other (please specify) ___________________________________________________
Additional Comments
Please use this space if there is any additional information which you feel would be helpful for me to know:

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
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______________________________________________________________________________
LIVING WITH UNCERTAINTY: 
PSYCHOSOCIAL NEEDS OF CHILDREN COPING WITH A PARENT’S CANCER

INTERVIEW GUIDE – WELL PARENT OR CAREGIVER

NOTE: This interview guide will be used in a flexible and open manner. Although each question is useful in understanding the experience for the participant, it is important to remember that following the participant’s lead is of great importance. As such, not all questions may be asked.

The qualitative interview guides are guides only and expected to evolve over the course of the study. Any revisions will remain reflective of the original study objectives and as such revisions will not be submitted for REB amendment approval.

Finally based on information provided on the demographic information forms, the well parent may not be the partner of the person living with cancer, and therefore use of language such [your child’s parent who has cancer] will be used in the interview. In addition as the person taking part in the interview may not be a parent or partner, language such as [caregiver] or [the person you are caring for] or [the child you are helping to care for] will be used.

Introductory Comments (Reason for Interview):

Hello _________________________ I’m Gabrielle.
Thank you for taking the time to meet with me today. In this interview I will be asking you some questions to help me understand your experience in your role as the well parent OR [caregiver]. I also hope to understand your thoughts about your child (children)’s experience OR [the experiences of the child (children) you are helping to care for]. By learning about your experience, it will help me greatly with my research. If you feel you cannot answer a question, or if you want to stop the interview, please let me know. This interview will take about one hour. I will be audio-taping it so I will have a record of what we talked about. Finally it is important to let you know that everything will be kept confidential as indicated in the Consent Form which we reviewed and you signed.

Topic A: Information about Parent’s Cancer Status (Meaning of Experience)

The Illness Time Line (Appendix 14) which the participant completed prior to the interview will be used for the initial topic of the interview

1) First of all could we start with when your partner OR [your child’s parent; or the person you are caring for] was diagnosed with cancer? With regard to the Illness Time Line you completed, I can see that he/she was diagnosed _______________
Prompts:
   a) Can you tell me what that was like for you?
   b) What did you think / how did you feel when you found out?

2) I can also see from the time line that he/she has had _____________________________
   (treatment)

Prompts:
   a) What has your partner’s treatment been like for your family?
      OR [your child’s parent’s treatment; or the treatment of the person you are caring for]
   b) Did he/she lose his/her hair with treatment?
      • What did you think of that?
      • What did he/she think?
      • What did your child (children) think?

3) How do you make meaning of your partner’s illness?
   OR [the illness of your child’s parent; or the illness of the person you are caring for]

Prompts:
   a) Have you wondered about:
      o What is the hardest part for you, for your partner [for your child’s parent; or the
         person you are caring for], and for this child (children)?
      o Why this has happened to you and your family, OR to [your child’s parent; or the
         person you are caring for]?
      o What effects has cancer had on your lives (negatively and positively)?

NOTE – if the participant completed the Parent or Caregiver Distress Rating Scale, it will be
discussed at this point in the interview.

**Topic B: Caregiving**

1) Can you tell me about your caregiving experience – what it is like for you to care for your
   partner OR [your child’s parent; or the person you are caring for] while he/she is sick?

Prompts:
   a) What would a typical day look like for you with caregiving?
   b) What makes it difficult for you to care for your partner OR [your child’s parent; or the
      person you are caring for]?
   c) Is there anything else about your caregiving experience which you feel is important for
      me to know?
**Topic C: Parenting or Caring for the Child (Children)**

1) Could you tell me what it has been like to parent or care for this child (children) while caring for your partner OR [or the person you are caring for]?

2) When you found out that your partner OR [your child’s parent; or the person you are caring for] had cancer, what thoughts and feelings did you have as a parent or caregiver?

Prompts:

How did you tell your child (children) [or the child (children) you are helping to care for] about this person’s cancer?

- What words have you used to talk about cancer?
- What was this child’s (or children’s) reaction to the news?
- How did you help him/her (or them) make sense of what is happening?
  - What is your biggest worry about this child (or children)?

a) If there was one piece of advice you could give other parents or caregivers who are living a similar parenting or caregiving experience what would that be? Why?

*NOTE – if the parent or caregiver indicates at any time during this section that they have had a discussion with the child (children) about the person with cancer dying, I will ask the following questions:

- When you told this child that ____________ was dying what was his/her reaction?
- How has this child been since that conversation?
- What would you like me to know about helping this child to understand?

**Topic D: Your Relationship with This Child (or Children)**

Having a parent who has cancer can be hard for children because they may not be able to talk to their parents (because of cancer and caregiving) about their thoughts and feelings. Cancer usually have a special relationship with each parent that has existed since birth. Cancer can affect this relationship – especially the emotional support for children.

1) It would help me to know about your relationship with this child (children) before your partner OR [your child’s parent; or the person who you are caring for] was diagnosed with cancer?

2) It would also be helpful to know about this child’s (children’s) relationship with his/her parent who has cancer.

Prompts – focusing on one child at a time if there is more than one child in the family:

a) Who would he/she go to when he/she was upset, or hurt?

b) What effect has your own worry had on your relationship with this child?

c) Does your child talk to you about his thoughts and feelings?
  i. What things has he shared with you?
**Topic E: Taking Care of You**

Parenting and caregiving can be exhausting especially when doing them at the same time. It would be helpful to spend some time talking about taking care of you.

1) What helps you cope with all you have to do as a parent or caregiver?
2) What role do family and friends play in helping you when things make it difficult to cope?

**Topic F: Supports in the Community**

**Supports for yourself**

Can we talk about your experience with supports in the community?

1) What supports have you used since your partner OR [your child’s parent; or the person who you are caring for] was diagnosed?

Prompts:
   a) What have you found helpful?
   b) What have you found unhelpful?

3) If there could be one particular support that you needed to help you in your parenting or caregiving experience but couldn’t find or access, what would that be? Why?

**Strategies and supports for your child [or the child you are helping to care for] and/or you as a parent [or caregiver]**

1) What has your experience been with supports in the community to help this child (children)?

Prompts:
   a) What has been helpful this child make sense of what is happening?
   b) How supportive has this child’s school been?

2) One of the reasons I am talking with you, the parent with cancer, and your child OR [the child you are helping to care for], in addition to other families coping with a similar situation, is so that I can find out about things that would help.

Prompts:
   a) If you could think of one thing that would help this child or another child coping with the same thing, what would it be?
   b) Where are the gaps in supports for children?
   c) What needs to be in place for children living with a parent with cancer?
   d) What would you like to see in place for parents of children living with a parent with cancer?
Conclusion

I have one more question …

Do you have anything else you would like to tell me about your parenting and/or caregiving experience?

Thank you (parent’s or caregiver’s name). You have really helped me understand your experience. What you have shared with me today will help me with my research which will lead to developing supports for children and parents/families living a similar experience.
LIVING WITH UNCERTAINTY:  
PSYCHOSOCIAL NEEDS OF CHILDREN COPING WITH A PARENT’S CANCER  
INTERVIEW GUIDE – PARENT LIVING WITH CANCER

NOTE: This interview guide will be used in a flexible and open manner. Although each question is useful in understanding the experience for the participant, it is important to remember that following the participant’s lead is of great importance. As such, not all questions may be asked.

The qualitative interview guides are guides only and expected to evolve over the course of the study. Any revisions will remain reflective of the original study objectives and as such revisions will not be submitted for REB amendment approval.

Introductory Comments (Reason for Interview):

Hello _______________________. I’m Gabrielle. Thank you for taking the time to meet with me today. In this interview I will be asking you some questions to help me understand your experience as a parent who is living with cancer. I also hope to understand your thoughts about your child (children)’s experience. By learning about your experience, it will help me greatly with my research. If you feel you cannot answer a question, or if you want to stop the interview, please let me know. This interview will take about one hour. I will be audio-taping it so I will have a record of what we talked about. Finally it is important to let you know that everything will be kept confidential as indicated in the Consent Form which we reviewed and you signed.

Topic A: Information about Parent’s Cancer Status (Meaning of Experience)

The Illness Time Line (Appendix 14) which the parent completed prior to the interview will be used for the initial topic of the interview

1) First of all could we start with when you first found out you had cancer? With regard to the Illness Time Line you completed, I can see that you were diagnosed ____________

Prompts:
 a) Can you tell me what that was like for you?
 b) What did you think / how did you feel when you found out?

2) I can also see from the time line that you had __________________

(treatment)

Prompts:
 a) What has your treatment been like for your family?
b) Did you lose your hair with treatment?
   • What did you think of that?
   • What did your partner (or caregiver) think?
   • What did your child (children) think?

3) How do you make meaning of your illness?

Prompts:
   a) Have you wondered about:
      • What is the hardest part about your cancer for you, for your partner (or caregiver),
        and for your child (children)?
      • Why this has happened to you and your family?
      • What is important to you in your family and in life?
      • Has cancer led to any positive experiences?

NOTE – if the participant completed the Parent or Caregiver Distress Rating Scale, it will be discussed at this point in the interview.

**Topic B: Parenting**
Could you tell me about what it has been like to parent while you have been living with cancer?

1) When you found out that you had cancer, what thoughts and feelings did you have as a parent?

Prompts:
   a) How did you tell your child (children) about your cancer?
      • What words have you used with him/her about your cancer?
      • What was your child’s (children’s) reaction to the news?
      • How did you help him/her make sense of what is happening?
         • What is your biggest worry about your child (children)?

b) If there was one piece of advice you could give other parents who are living a similar parenting experience what would that be? Why?

*NOTE – if the parent indicates at any time during this section that they have had a discussion with the child (children) about dying I will ask the following questions:
   • When you told your child that you are dying what was his/her reaction?
   • How has your child been since that conversation?
   • What would you like me to know about helping your child to understand?
**Topic C: Your Relationship with Your Child (Children)**

Having a parent who has cancer can be hard for children because they may not be able to talk to their parents (because of cancer and caregiving) about their thoughts and feelings. Children usually have a special relationship with each parent that has existed since birth. Cancer can affect this relationship – especially the emotional support for children.

1) Tell me about your relationship with your child before you were diagnosed with cancer? And his/her relationship with your partner or caregiver?

Prompts – focusing on one child at a time if there is more than one child in the family:
   a) Who would he/she go to when he/she was upset, or hurt?
   b) What effect has your cancer had on your relationship with your child?
   c) Does your child talk to you about his/her thoughts and feelings?
      i. What things has he/she shared with you?

**Topic D: Supports in the Community**

**Supports for yourself**

It would be helpful to talk about your experience with supports in the community.

1) What supports have you used since your diagnosis?

Prompts:
   a) What have you found helpful?
   b) What have you found unhelpful?

2) If there could be one particular support that you needed but couldn’t find or access, what would that be? Why?

**Strategies and supports for your child and/or you as a parent**

1) What has your experience been with supports for your child (children) in the community?

Prompts:
   a) What has been helpful to make your child (children) make sense of what is happening with you?
   b) How supportive has your child’s (children’s) school been?

2) One of the reasons I am talking with you, your partner or caregiver, and child (and families coping with a similar situation) is so that I can find out about things that would help.
Prompts:
  a) If you could think of one thing that would help your child or another child coping with
     the same thing, what would it be?
  b) Where are the gaps in supports for children?
  c) What would you like to see in place for children living with a parent with cancer
  d) What would you like to see in place for parents of children living with a parent with
     cancer?

Conclusion
I have one more question …

Do you have anything else you would like to tell me about your experience parenting while
living with cancer – anything we have not talked about yet?

Thank you, (parent’s name). You have really helped me understand your experience parenting
while living with cancer. What you have shared with me today will help me with my research
which will lead to developing supports for children and parents or caregivers living a similar
experience.
NOTE: This interview guide will be used in a flexible and open manner. Although each question is important in understanding the experience for the participant, it is important to remember that following the participant’s lead is of great importance. As such, not all questions may be asked.

The qualitative interview guides are guides only and expected to evolve over the course of the study. Any revisions will remain reflective of the original study objectives and as such revisions will not be submitted for REB amendment approval.

IMPORTANT – in this interview I will be using the language used by the parents when talking with their child (children) about the situation with the ill parent. In addition, it is important that I follow the lead of the child; I will not use words or phrases that are ahead of the child (children).

Introductory Comments (Reason for Interview)

Hello _______________________. I’m Gabrielle.
Thank you for coming to talk with me today. I know your mother or father told you about what we are going to talk about. I have some questions that I would like to ask you to help me understand what it is like for you to have a parent who has cancer. In fact I am going to meet with a lot of children who also have a parent who has cancer. Do you have anything you would like to ask me before we get started (pause if child does want to ask a question)?

Before we get started, I thought I’d let you know that if you feel you cannot answer a question, or if you want to stop the interview, please let me know. This interview will take about 45 minutes and I will be audio-taping it so I will have a record of what we talked about. Everything we talk about will be kept confidential (explain to younger child).

Topic A:   Biographic Information

1) First of all could we start with you telling me a bit about you?

Prompts:
   a)   How old are you?
   b)   What is your favourite thing to do?
   c)   What grade are you in?
   d)   What would you like me to know about you?
2) Could you tell me about your family and friends?
Prompts:
   a) Your parents?
   b) Brothers and sisters?
   c) Any pets?
   d) Can you tell me about your friends?
   e) What else would you like me to know about you and/or your family?

Topic B: Information about Child’s Parent who has Cancer (Meaning of Experience)

1) It would be helpful if you could tell me about your parent who has cancer

Prompts:
   a) How old is he or she?
   b) What do you like to do with him or her?

NOTE: Prompts below are based on the Illness Time Line (Appendix 14) – child completed individually or with help from a parent prior to the interview

2) I can see that you have done a lot of work on the time line.

Prompts:
   When you found out about your parent’s cancer:
   a) What did you think?
   b) What did you feel?

3) On the time line, I can see that your mother/father had ____________________ treatment  
   (surgery, chemotherapy; radiation)
   a) What was it like for you when your parent was going through treatment?
   b) Did your parent lose his/her hair? What did you think about that?

Thank you for helping me to understand about your parent’s cancer.

Topic C: Feelings and Level of Worry (Distress) - Worry Meter (Appendix 16)

I have something that would help me understand more about you and your mother/father’s cancer.

1) This is something I call a Worry Meter.
   (Show the child and talk about how to complete the Worry Meter).
The idea is that you put 3 circles on the meter. Help a younger child to complete it. Older children can take time to complete it. If a child does not wish to complete it, that will be fine.

2) Questions for discussion once child has completed the Worry Meter

Prompts
   a) If you could tell me one thing that you worry about the most with your parent’s cancer, what would that be?
   b) Does your worry get too big for you? If it does, what do you do to help yourself with it?

**Topic D: Communication of Your Thoughts and Feelings with Parents**

**Pre-cancer**
1) When children have to cope with something hard, they usually talk to their mother or father

Prompts
   a) Before you found out about your mother/father’s cancer, last year for example, who did you talk to when you were having a hard time with something?
   
2) Who do you talk to about your parent’s cancer?
   If the child indicates the well parent or caregiver,
   a) Does your parent or ________________ (name of caregiver) understand?
   b) When you talk with your parent, how do you feel better about things?
   c) Is there someone else who you can talk to?

*NOTE – if the child lets me know at any time during the interview that they know their parent is dying I will follow the child’s lead possibly asking the following:

- When you learned that your parent is dying what did you think/feel?
- How have you been since that conversation with your parent(s) or with ________________ (name of caregiver)?
- Are you able to talk anymore about what is happening to your parent with your parents or ________________ (name of caregiver)?

What you have just told me about talking with your parent(s) is important, thank you.
Topic E: The Well Parent or Caregiver

1) Sometimes children say they have to do one of the following things to help their parent:
   a) Be strong
   b) Be positive
   c) Worry about their mother/father
   d) Try to make their mother/father feel better
   What do you think about any of those?

2) If there was one thing you would like your parent(s) or caregiver to know about what you need – what would help you the most – what would that one thing be?

Topic F: Strategies and Supports

You’ve told me … give a short summary of what the child’s responses have been about his parent’s cancer. One of the reasons I am talking to you and to other children who have a parent who has cancer is so that I can find out about things that would help.

Maybe we can spend some time talking about what other people or things help you

Prompts:
1) Can you talk with your friends know about your mother / father?
   a) How supportive are your friends? Do they understand?
2) What about your teacher – does he / she know?
   a) Can you talk to him / her when you are having a hard time?
3) If you could think of one thing that would help you or another child who has a parent who has cancer, what would it be?
4) What is one thing you would want other parents to know to help their children coping with a parent who has cancer?
5) And what is one thing you could tell people like me about how best to help children and parents like you?

Conclusion

Do you have anything else you would like to tell me about your mother or father and their cancer or how you think/feel about it – anything we have not talked about yet?

Thank you _______________. You have done a really good job helping me understand what you think and feel about having a parent who has cancer. What you have shared with me today will help me, and other people like me, to think of things that will help children and parents just like you.
Illness Time Line (Adult)
Completed by Parent with Cancer OR Well Parent or Caregiver

| ID# - Well Parent or Caregiver | _______________ |
| ID # - Parent with Cancer | _______________ |
| ID # - Child | _______________ |
| Date | _______________ |

Above the time line on the following page, please indicate the following to provide information about your cancer OR [your partner’s cancer; or the person’s cancer who you are caring for] from diagnosis to this point in time:

- When you were diagnosed [or the person with cancer]
- When you had surgery (if appropriate) [or the person with cancer]
- When you started and finished chemotherapy (if appropriate) [or the person with cancer]
- When you started and finished radiation (if appropriate) [or the person with cancer]
- When your cancer spread (if appropriate) [or the person with cancer]
- Any other important times which you would like to add to the time line with regard to your cancer [or the person with cancer]

Below the time line on the following page, please indicate the following about your child [or the child you are caring for] to provide information about this child’s understanding of your cancer [or the person with cancer]:

- When you told this child about the diagnosis
- When you told this child important news about the cancer and/or treatment
- Any other important times which you would like to add to the time line with regard to this child and the cancer

If the child wishes to complete the Time Line without parental or caregiver assistance, that is fine.
Illness Time Line (Adult)

ID# - Well Parent or Caregiver
ID # - Parent with Cancer
ID # - Child
Date

Developed by Gabrielle Pitt (2000)
Illness Time Line (Child)
Time Line of Your Mother or Father’s Cancer

ID# - Well Parent or Caregiver
ID # - Parent with Cancer
ID # - Child
Date

Above the time line on the following page, it would be helpful if you could put any of the following:

- When you found out about your mother / father’s cancer
- What you remember about the treatment your mother / father had
  - Surgery?
  - Chemotherapy?
  - Radiation?
- Any other important times which you would like to add to the time line with regard to your mother father’s cancer

Below the time line on the following page, it would be helpful if you could write or draw how you felt about any of the points on the time line.
Illness Time Line (Child)
Time Line of Your Mother or Father’s Cancer

ID# - Well Parent or Caregiver
ID # - Parent with Cancer
ID # - Child
Date

Developed by Gabrielle Pitt (2000)
Worry Meter for Children

Instructions:

On the Worry Meter, circle the number that matches:

1) The highest your worry has been since you found out your parent has cancer (with one colour)
   a) Why?
      ______________________________________
      ______________________________________

2) The lowest your worry has been since you found out your parent has cancer (with another colour)
   b) Why?
      ______________________________________
      ______________________________________

3) The number where your worry about your parent is today (with another colour)
   a) Why?
      ______________________________________
      ______________________________________

Developed by Gabrielle Pitt (2000)
**Parent or Caregiver Distress Rating Scale**

**Instructions:**
With 1 being the least, and 10+ being the highest, on the Distress Rating Scale please circle the number that matches:

1) The highest your distress has been since you were diagnosed, or since your partner or the person you are caring for was diagnosed
   a) Give a description of the circumstances (when and why).

   _______________________________________________________
   _______________________________________________________
   _______________________________________________________
   _______________________________________________________

2) The lowest your distress has been since you were diagnosed, or since your partner or the person you are caring for was diagnosed
   a) Give a description of the circumstances (when and why).

   _______________________________________________________
   _______________________________________________________
   _______________________________________________________
   _______________________________________________________

3) The level your distress is today
   a) Give a description of the circumstances (why).

   _______________________________________________________
   _______________________________________________________
   _______________________________________________________
   _______________________________________________________

(Adapted from Worry Meter for Children Pitt, G., 2000)
LIVING WITH UNCERTAINTY: PSYCHOSOCIAL NEEDS OF CHILDREN COPING WITH A PARENT’S CANCER

SOURCE NOTES

Participant #1: Identified Participant (Parent with Cancer)

ID: 
Number 

1. First Name: ____________________________  2. Last Name: ____________________________

3. Contact information: ____________________________ Telephone number 

4. Address: __________________________________________________________

5. Participant’s cancer type: __________________________________________

6. Participant was identified by:
   a) CALM Study Team r
   b) Pancreatic Cancer Study Team r
   c) Young Adults Study Team r
   d) Health Professional r
   Specify: __________________________________________________________

7. If 1/2/3 – Referring study status:
   (E.g., Active; completed; withdrawn, etc.)

Initials ____________
8. Notes from referring team / health professional:
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

9. **Recruitment (identified participant)**

a) Introductory letter was mailed/given on: ______________
   DD-MM-YYYY

b) Participant was approached: __________________________
   (E.g.: in clinic, over the telephone)
   on ________________ at _____:______
   DD-MM-YYYY HH MM

c) Did participant give verbal consent to participate in the research study?
   1) Yes
   2) No
   Proceed to point #29; Declined to Participate
   OR point #30; Ineligible (page 15)

d) Appointment was scheduled for_________________ at _____:______
   DD-MM-YYYY HH MM
   at ______________________
   (clinic, home, telephone, etc.)

e) Consent Checklist: Consent form was:
   1) Given to participant
   2) Mailed to participant

f) Was consent form reviewed with participant?
   1) Yes
   2) No

g) Did participant understand the study and the importance of consent?
   1) Yes
   2) No
h) Consent form was signed on: ____________________________

__________________________  ____________________________
DD-MM-YYYY

i) Was a signed copy of the consent form given to the participant?

1) Yes  

2) No

j) Additional Notes

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

10. Interview (identified participant)

a) Interview was conducted by __________________________

b) Was participant (patient) able to participate in the interview?

1) Yes  

2) No

c) Date/Time of interview: __________________________ at _____:______

DD-MM-YYYY           HH      MM

d) Location of interview: _________________

Initials______________
e) Length of interview: __________________________

f) Additional notes:
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

h) Interview was transcribed on _______________ by _________________________
   DD-MMM-YYYY

i) Interview transcription was verified on _______________ by _________________
   DD-MMM-YYYY
11. Participant # 2 is the:
   a) well parent
   b) caregiver

12. First Name: __________________________
13. Last Name: __________________________

14. Contact information: ______________________________________________________
   Telephone number

15. Address: _________________________________________________________________
       ________________________________________________________________

16. Recruitment (participant # 2)

   a) Participant # 2 was approached: ___________________________________________
      (E.g.: in clinic, over the telephone)
      on ___________________ at __________
      DD-MMM-YYYY           HH        MM

   b) Did participant give verbal consent to participate in the research study?
      1) Yes   r  2) No    r
      Proceed to point #29; Declined to Participate (page 15)

   c) Appointment was scheduled for ___________________ at __________
      DD-MMM-YYYY           HH        MM
      at ______________________
      (clinic, home, telephone, etc.)
d) Consent Checklist: Consent form was:
1) Given to participant  
2) Mailed to participant

e) Was consent form reviewed with participant?
1) Yes  
2) No

f) Did participant understand the study and the importance of consent?
1) Yes  
2) No

g) Consent form was signed on: _________________ DD-MMM-YYYY

h) Was a signed copy of the consent form given to the participant?
1) Yes  
2) No

i) Additional Notes
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Initials_________

17. Interview (participant # 2)

a) Interview was conducted by ____________________________

b) Date/Time of interview: __________________ at ______:______
   DD-MMM-YYYY       HH      MM

c) Location of interview: _________________________

d) Length of interview: __________________________

e) Additional notes:
   ___________________________________________
   ___________________________________________
   ___________________________________________
   ___________________________________________
   ___________________________________________
   ___________________________________________

f) Interview was stored on a UHN encrypted storage unit
   1) Yes  r
   2) No  r

g) Interview was transcribed on _______________ by _________________________
   DD-MMM-YYYY

h) Interview transcription was verified on _______________ by _________________
   DD-MMM-YYYY

Initials____________

21. Recruitment (child 6 – 18 yrs.)

a) Participant was approached: ____________________________________________
   (E.g.: in clinic, over the telephone)

   on _________________ at _____:______
   DD-MMM-YYYY HH MM

b) Did participant give assent/verbal consent to participate in research study?
   1) Yes r
   2) No r
   Proceed to point #29; Declined to Participate (page 15)

c) Was assent (for child 6-16 yrs.) or consent (for child 17-18 yrs.) reviewed with participant?
   1) Yes r
   2) No r

d) Did participant understand the study and the importance of assent/consent?
   1) Yes r
   2) No r

e) Assent/consent was given by child on ________________
   DD-MMM-YYYY

f) Consent form was signed by: _____________________________ on ________________
   DD-MMM-YYYY

Initials__________
g) Additional Notes
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

22. Interview (child 6 – 18 yrs.)

a) Interview was conducted by __________________________

b) Date/Time of interview: _________________ at _____:______
   DD-MMM-YYYY           HH      MM

c) Location of interview: _________________________

d) Length of interview: __________________________

e) Child was accompanied by: __________________________________________

f) If child was accompanied by an adult companion/caregiver (not already consented and participating in this study), was an Informed Consent Form for Companions signed?
   1) Yes  
   2) No  

Initials__________
g) Informed Consent Form for Companion was signed by: ____________________ on __________________ DD-MMM-YYYY

h) Additional notes:
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

i) Interview was stored on a UHN encrypted storage unit
   1) Yes  r  2) No  r

j) Interview was transcribed on _______________ by _________________________
   DD-MM-YYYY

k) Interview transcription was verified on _______________ by _________________________
   DD-MM-YYYY
ID: __________________  Completion Date: __________________  
Number  

**Additional Interview (Child # 2; 6-18 yrs.)**

23. First Name: ____________________  
24. Last Name: ____________________

25. Child participant # 2 was identified by:  
a) ill parent  
b) well parent/caregiver

26. **Recruitment (child # 2; 6 – 18 yrs.)**

a) Participant was approached: ____________________________________  
   (E.g.: in clinic, over the telephone)  
   on __________________ at _____:______ 
   DD-MMM-YYYY         HH        MM

b) Did participant give assent/verbal consent to participate in research study? 
   1) Yes r  
   2) No r  
   Proceed to point #29; Declined to Participate (page 15)

c) Was assent (for child 6-16 yrs.) or consent (for child 17-18 yrs.) reviewed with participant?  
   1) Yes r  
   2) No r

d) Did participant understand the study and the importance of assent/consent?  
   1) Yes r  
   2) No r

e) Assent/consent was given by child on ____________________  
   DD-MMM-YYYY

f) Consent form was signed by: ___________________________ on ________________ 
   DD-MMM-YYYY

Initials_________
27. Interview (child # 2; 6 – 18 yrs.)

a) Interview was conducted by __________________________

b) Date/Time of interview: ______________________ at ______:______
   DD-MMM-YYYY           HH      MM

c) Location of interview: _________________________

d) Length of interview: __________________________

e) Child was accompanied by: ________________________________

f) If child was accompanied by an adult companion/caregiver (not already consented and participating in this study), was an Informed Consent Form for Companions signed?
   1) Yes    2) No

Initials__________

g) Informed Consent Form for Companion was signed by: _____________________________ on ________________ DD-MMM-YYYY

h) Additional notes:

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

i) Interview was stored on a UHN encrypted storage unit
   1) Yes  
   2) No

j) Interview was transcribed on _______________ by _________________________

   DD-MMM-YYYY

k) Interview transcription was verified on _______________ by _________________

   DD-MMM-YYYY
28. Written Description of Informed Consent Process

Please provide written narrative of the consent process for the participant family. Please provide questions asked and answers provided, if any.

______________________________________________________________________
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______________________________________________________________________
______________________________________________________________________
29. Declined to participate

a) Refusal to participate in research study expressed by:
b)  
   1) Identified participant  
      a. Reason for refusal:  
      ___________________________________________________________________
   
   2) Participant # 2  
      a. Reason for refusal:  
      ___________________________________________________________________
   
   3) Child 6-18 yrs.  
      a. Reason for refusal:  
      ___________________________________________________________________
   
   4) Child # 2 6-18 yrs.  
      a. Reason for refusal:  
      ___________________________________________________________________
   
   c) Did participant give permission to collect basic information?  
      1) Yes  
      2) No  

d) If Yes, proceed to Demographics (page 17 of Source Notes)

e) Additional notes:  
_________________________________________________________________  
_________________________________________________________________  
_________________________________________________________________

30. Ineligible to Participate

a) Participant family was determined to be ineligible to participate:  
   Yes  
   r  
   No 

b) Reason(s) for ineligibility (please specify):  
   ____________________________________________

c) Additional notes:
_________________________________________________________________  
_________________________________________________________________  
_________________________________________________________________

Initials___________
31. Consent Withdrawal

a) Consent withdrawal from study was requested by
   1) Identified participant  
   2) Participant #2  
   3) Child 6-18 yrs.  
   4) Child #2 6-18 yrs.

b) Date of withdrawal: ____________________  
   DD-MMM-YYYY

c) Reason for withdrawal:
   a. ______________________________________________________

d) Additional notes:
   ______________________________________________________
   ______________________________________________________
   ______________________________________________________
   ______________________________________________________
   ______________________________________________________
   ______________________________________________________
   ______________________________________________________
Demographics

r Family members agreed to participate in research study
r Family members refused to participate in research study but give permission to collect basic information

1. Identified participant – Parent Living with Cancer
   a) Sex: ______________
   b) Age: ______________
   c) Relationship with the child:
      1) Mother
      2) Father
      3) Other – Specify: ______________

2. Participant #2 – Well Parent or Caregiver
   a) Sex: ______________
   b) Age: ______________
   c) Relationship with the child:
      1) Mother
      2) Father
      3) Other – Specify: ______________

3. Child 6-18 yrs.
   1. Sex: ______________
   2. Age: ______________
   3. Grade: ______________

4. Child #2, 6 – 18 yrs.
   a) Sex: ______________
   b) Age: ______________
   c) Grade: ______________
5. Additional notes:

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

Initials____________