

You Matter:
Retrospectively Exploring the Needs of Adolescents who had a Sibling with Cancer

by

Genevieve Grace Shireen Stonebridge
B.A., The University of Victoria, 2010

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of the Requirements for the Degree of

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Supervisory Committee

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Abstract

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Previous research has started the discussion about the impact of unmet needs on the psychosocial adjustment of well-siblings of children and youth diagnosed with cancer. The purpose of this qualitative study was to retrospectively explore the needs of adolescents who had a brother or sister, who was diagnosed with, treated for and who lived through cancer. The findings and knowledge mobilization project from this study will extend the literature and will also bring information to counsellors, social workers, doctors, nurses, cancer support agencies, parents, family members, friends, teachers, and—importantly—to well-siblings themselves. Narrative data were collected from 7 adult sisters who reflected on their adolescent-aged experience of being the well-sibling of a sister ($n=4$) or brother ($n=3$) who was diagnosed with and treated for cancer. Data were analyzed using thematic analysis and 7 need-based themes identified from the data are reported. Further research is recommended, and implications from the present study are discussed.

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*“Even after all these years the sun never says to the earth, “You owe me.”
Look at what happens with a love like that. It lights the whole sky.” –Hafiz*

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Dedication

This thesis is dedicated to my little sister Jasmine Angelica Norina Stonebridge.
Jazzy, you matter so very much to me.

Chapter 1

Introduction & Literature Review

According to Childhood Cancer Canada, there are approximately 10,000 children (0-19 years-of-age) living with cancer today in Canada, and approximately 1,500 new cases diagnosed yearly (Childhood Cancer Canada Foundation, 2011). In 2014, it was estimated 1,450 children were diagnosed with cancer (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2014, p. 33). Statistics Canada (2013) cites that in 2011, for every Canadian family there were approximately 1.8 children. Thus, it is possible that most children and youth diagnosed with cancer will have one or more siblings in their families. If approximately 1,500 new cases are diagnosed yearly, then these families of newly diagnosed children and youth will include approximately 1200 well-siblings. The sibling bond is potentially one of the longest relationships of a lifetime (McGoldrick, Watson & Benton, 2005, p. 153). Engaging with brothers and sisters sets a formative foundation for interaction in future relationships and affects individual development throughout the lifespan (McGoldrick et al., 2005, p. 153; Woodgate, 2006). Family dynamics, birth order, gender, age spacing, and life cycle issues have great impact not only on how family and sibling relationships unfold (Brody, 1998; McGoldrick et al., 2005, p. 154), but also on the individual development and functioning of children (Brody, 1998). How then is a brother or sister impacted when their sibling is diagnosed with and treated for cancer? What is the sibling experience and what are the needs of siblings who have a sibling with cancer? These are questions I hoped to answer through my research study. In my study, I use the terms "well-sibling" and "sick-sibling" to refer to the undiagnosed and diagnosed siblings, respectively.

Cancer is an unwelcome guest in any family, and all members will be impacted by its

presence. Each member of every family will experience varying degrees of disruption and distress. While the experiences of the sick-sibling and their caregivers have been explored extensively over the past 50 years (Wilkins & Woodgate, 2005), research about the experience of well-siblings is still in its infancy, requiring more attention and focus (Alderfer, Long et al., 2010; Alderfer & Noll, 2006; Buchbinder, Casilas & Zeltzer, 2011; Wilkins & Woodgate, 2005). Alderfer et al. (2010) reported that there were more studies published between 1999 and 2009 on the experience of a well-sibling in a family with a sick-sibling with cancer, than in the previous 40 years combined. Wilkins and Woodgate (2005) reviewed 27 qualitative studies, published between 1979-2004, all of which focused on the well-sibling experience of childhood cancer diagnosis and treatment. Upon review of the 27 articles, Wilkins and Woodgate (2005) criticized the reviewed studies for often using a generalized sampling process, combining siblings across ages and developmental stages. They argued that this type of heterogeneous sampling (e.g., when a 5-year-old child's experience is lumped in with that of a 16-year-old's) makes it difficult to make inferences based upon the developmental level of the sibling. (Alderfer and colleagues (2010) urged future researchers to focus not only on particular age groups of siblings, but also on other possible moderators of adjustment, such as time since diagnosis and gender of both the well and sick-sibling.) From their systematic review of previous research, Alderfer et al. (2010) concluded overall that research on the sibling experience was lacking in several ways, and that despite calls over the past 10 or so years for more rigorous research focusing on the experience of well-siblings, "these calls have not been answered" (p. 799).

What is clear from previous research is that well-siblings are at risk for psychosocial adjustment issues (Alderfer et al., 2010; Alderfer & Hodges, 2010; Alderfer & Noll, 2006; Malone & Price, 2012; Woodgate, 2006) including disruption to healthy emotional functioning

and adjustment (e.g., depression, anxiety, and social withdrawal) (Alderfer, et al., 2010; Houtzager, Grootenhuis, Caron & Last, 2004; Patterson, Millar & Visser, 2011). While a sibling's cancer diagnosis and treatment do not *cause* psychosocial adjustment difficulties in well-siblings, well-siblings do report being impacted both psychologically and emotionally (Malone & Price, 2012; Woodgate, 2006). Alderfer and Hodges (2010), for example, reported that over half of the well-siblings in their study reported moderate to severe cancer-related posttraumatic stress symptoms. Lown et al. (2013) recently concluded that siblings of children with cancer were more likely, in comparison to childhood cancer survivors and a control group, to engage in risky behaviour with alcohol as adults. Increased risky behaviour was associated with the well-sibling's experience of loneliness, isolation, anxiety, depression, and general psychological distress during their sibling's cancer treatment. Psychosocial adjustment difficulties often develop as a result of one or more of well-siblings' essential needs not being met during their sibling's cancer treatment (Barrera, Chung, Greenburg & Fleming, 2002; Malone & Price, 2012; O'Shea, Shea, Robert & Cavanaugh, 2012; Patterson et al., 2011; Patterson et al., 2014). Despite paediatric cancer research having begun in the late 90s to include the experience of well-siblings, only a small and relatively recent body of research has specifically focused on and documented the needs of well-siblings (for review, see also Alderfer et al., 2010; O'Shea et al., 2012; Patterson et al., 2011; Patterson et al., 2014; Wilkins & Woodgate, 2005). In effect, siblings' needs continue to be neglected (Alderfer et al., 2010; Ballard, 2004; 2012; Murray, 1998; O'Shea et al., 2012; Patterson, et al., 2011; Wilkins & Woodgate, 2005; Woodgate, 2006).

Some research has explored the needs of well and sick-siblings jointly (DiGallo, 2003), and other research has considered the needs of well-siblings as a standalone group (Patterson et

al., 2011; Patterson et al., 2014). Patterson et al. (2014) explored the present needs of well-siblings who were “young people” (aged 12-24 years) who had a sibling with cancer, and provided evidence that well-siblings have needs that often go unmet. DiGallo (2003) supported investigating the perspective of well-siblings *after* treatments and recovery because, retrospectively, siblings are more likely to reflect in ways about their experiences, which, in the past, could have been “too threatening and explosive” to talk about at the time (p. 500). Lehna (1998) suggested the perspective of grown well-siblings offers a different insight because adults are articulate and able to provide valuable information with hindsight reflection. In my search of the literature, I could find no study reporting the experience and needs of the adolescent well-sibling looking exclusively from the retrospective vantage point of the adult who was an adolescent when their sibling was diagnosed with and treated for cancer.

Accordingly, my objective for my thesis was to follow and explore DiGallo (2003) and Lehna’s (1998) lines of thinking that the retrospective perspective of adult siblings would offer a different and potentially helpful insight into the needs of adolescent siblings of children and youth living with cancer. I aimed to address this perspective and some of the other aforementioned gaps in the literature, by focussing specifically on the adolescent sibling experience from the vantage point of adults who were adolescents (defined for the present study as ages 11-18) when their sibling was diagnosed with, treated for, and survived cancer. Exclusionary criteria specifically stated that sick-siblings were two years past treatment.

Before providing a review of the literature and established findings on the experience of siblings in general, and especially of adolescent-age well-siblings, of children diagnosed with and subsequently treated for cancer, I first situate myself as researcher. As a qualitative researcher I believe it is imperative to locate myself within my research so my reader can

understand the lens through which I read the literature and went about collecting and analysing the data for this research. Thereafter, I provide a concise overview of adolescent development focusing on a description of the major tasks and milestones of adolescent development. Next, I provide a brief overview of need theory. I do this to create a background against which the reader can weigh and situate the findings from the literature I report with regard to the experience and needs of adolescent siblings of children and youth diagnosed with and treated for cancer.

Researcher Location

In 2001, there were 1300 new cases of children and youth diagnosed with cancer (Cancer Institute of Canada, 2001). In September of 2001, two weeks after my 18th birthday I was diagnosed with Hodgkin's Lymphoma and became one of those 1300. My life was irrevocably changed by my diagnosis, facing my mortality, the treatments of chemotherapy and radiation, and by my thankful recovery. While I consider my dance with cancer to be *my* journey, the experience also became my family's journey and each member was impacted in a different way.

Before, after, and during treatment my relationship with my parents was strong and supportive. They carried me through the process with great resilience, though I know the fear of losing one of their 'babies' impacted them deeply. My family stayed in a positive and supportive mindset during my treatments. A year and a half after completion of treatment, I allowed myself to acknowledge the fear and sadness that the experience of cancer had planted in my heart. I personally explored and healed what and how the experience had impacted both me and my parents, and allowed myself to admit the fear I had felt. This was an important and healing process for me, and I transitioned into a new understanding of myself and of life. While I considered myself healthy in my physical body, the psychological impact of my experiences had

not been fully understood until this awareness. The new awareness granted me the ability to hold space for both the darkness and the light of human existence.

However, in this journey of self-discovery I had not considered what it was like for my sisters, and particularly my 13-year-old little sister, Jasmine, who was a silent witness for much of the journey. At the time of my diagnosis my four sisters were 31, 29, 22 and 13 years of age. During my treatment and recovery all of my sisters were affected in different ways by my cancer. Jasmine, however, was the sibling who was most exposed to and affected by my treatment. The September I was diagnosed, Jasmine began Grade 8 in a new high school, a time of transition and change for most adolescents. However, she had the added stress of having a sick older sister getting the attention that she so desperately needed, but as she recalls, “felt too guilty to ask for.” Her life was disrupted differently from my other (older) siblings: first because of her age, and second, because my older sisters had already left home, it was just me and Jasmine who lived at home in the same house together with our parents. Our relationship was strained during this period, though at the time I disregarded the tension as “regular” sibling conflict. Being immersed in my own experience of the situation and as an adolescent myself, I did not have the perspective of how my illness affected Jasmine. It was not until 8 years later, through my work with the Canadian Cancer Society, when I gained insight into what the experience might have been like for her.

For the summers of 2010 and 2011, I had the privilege of working at the Canadian Cancer Society’s *Camp Goodtimes*. In this environment I worked as the participant support supervisor and my role was to provide psychosocial support for the participants of the camp. I learned from many of the children, youth, parents, and caregivers about how the cancer diagnosis impacts the whole family. Hearing stories of how some siblings felt supportive, protective, and

caring towards their sick-siblings while others felt neglected, frustrated, and angry offered me a valuable awareness into my own family and of their—and particularly my sister’s—experience.

I reflected on when I was first diagnosed and the behaviour of my little sister. It was September and, as I said earlier, Jasmine had just started Grade 8 at the high school I had graduated from the previous June. Then I got cancer, and any attention (including the attention she was used to getting as the youngest child) was completely directed towards me and my experience. This included the loss, or at least the diminishment, of attention from our parents, and older sisters. Her academic marks suffered and she hated going to school where, I later found out, she was being bullied. I did not know this at the time because she kept it all a secret, thinking that her pain was irrelevant in the face of my cancer. She reported that she did not want to be a burden. Somehow my family and I did not put the pieces together that my illness might have impacted and contributed to her rough transition; understandably we were all distracted with an illness that threatened my life. Therefore, my sister’s anguish was considered a normal teenaged reaction to life and unrelated to my cancer. She herself did not understand her reactions and why she felt that way. She was not included in my cancer process or treatment, and did not understand why I was so sick because no one had explained to her what chemotherapy was or what its side-effects were. Gratefully, inspired by my work with *Camp Goodtimes*, she and I started having conversations about what this time was like for her. With distance, time, and insight, healing began (and continues) between my sister and me. Further, through this research she and I have both come to a new understanding of how the cancer experience impacted her (and of course, our sibling relationship).

The reflection and perspective I gained by working with families who were affected by cancer at *Camp Goodtimes* is something I will be eternally grateful for. It was at *Camp*

Goodtimes where the first seed for this research was planted, and it inspired me to be curious about Jasmine's experience. These personal experiences and perspectives have elicited my desire to understand the lived experiences of adolescent siblings dealing with a sibling who has cancer more fully.

Going into this research, I hoped for the opportunity to deepen my relationship with my sister and to help other well-siblings. I have my own story about cancer and the impact on well-siblings; with this awareness, I've sought to allow the literature and the data collected to tell their own story. I navigated this journey by practicing reflexivity through discussions with my supervisor, keeping a researcher's field journal, journaling, and memoing. I also engaged in conversation with my family—my younger sister, older sisters and parents—and took good care of myself through active self-care and other support in the form of engaging in my own therapy and counselling (I discuss reflexivity in greater detail in Chapter 2).

Adolescent Development

Adolescence in North American society is typically thought of as beginning around age 11 (or in some cases the onset of puberty) and extending through to age 18 (Berk, 2008, p.6; Broderick & Blewitt, 2002, p. 314; Gray, Culpepper & Welsh, 2012, p. 22; Wade, Tavis, Saucier, & Elias, 2004, p. 515). Age 18 marks the start of the phase Arnett (2000) refers to as emerging adulthood (ages 18-25). As such, adolescence is a time of life that initiates the transition into adulthood, and is a period of marked physical, emotional, and cognitive change. Adolescence is socially constructed and discussed as a challenging period for many adolescents.

Adolescence is a developmental period largely associated with an intensification of emotions, moods (Wade et al., 2004, p. 516), and depressive symptoms, which are heightened during adolescence due to an increase in hormonal levels (Broderick & Blewitt, 2002, p. 281).

However, Broderick and Blewitt also suggested that hormonal changes more likely impact mood when they are combined with negative and stressful life events, such as changes in peer relationships, parental expectations, and academic problems (p. 282). In their study, Houtzager, Grootenhuis, Hoekstra-Weebers, and Last (2005), found adolescent (12-18 years) siblings whose brothers or sisters were diagnosed with cancer, experienced a lower quality of life (QoL) regarding cognitive skills and positive and negative emotions when compared to a non-affected peer group. Previous research (Alderfer et al., 2010; Alderfer & Hodges, 2010; Murray, 1998; Wilkins & Woodgate, 2005) has indicated that having a sibling diagnosed with cancer, and the ensuing changes to family dynamics, clearly qualifies as an instance of a stressful life event.

Central to the understanding of adolescence as a discrete developmental period, is the idea of adolescence being a time when persons explore the world around them and begin establishing identity (Broderick & Blewitt, 2002, p. 278). Indeed, one of the primary tasks of adolescent development is the search for identity (Erikson, 1968 cited in Broderick & Blewitt, 2002, p. 298). During this time, exploration of autonomy from the family and of personal goals and values are at the forefront of development (Gray et al., 2012, p. 25; Wade et al., 2004, p. 516). Erikson (1968) defined this life period of identity formation as an identity crisis (as cited in Broderick & Blewitt 2002, p. 298), which Marcia, Waterman, Matteson, Archer, and Orlofsky (1993) renamed “identity exploration” (as cited in Broderick & Blewitt, 2002, p. 299).

McGoldrick et al. (2005), suggested that sibling relationships play an important role in the identity development of an adolescent, stating “siblings can become the models for future relationships with friends, lovers, and other contemporaries” (p. 154). This line of thinking was supported by Wong, Branje, VanderValk, Hawk, and Meeus, (2010), who suggested that siblings impact each other’s identity formation by the way in which they interact with one another. The

McGoldrick et al. (2005) proposition that siblings act as role models and alter egos (p. 160) to one another, has been explained in two ways: through *identification* by noticing and perhaps imitating one another's behaviours; or through a *differentiation* process whereby siblings try to differentiate themselves from one another by asserting their individuality (Wong et al., 2010).

The adolescent's search for identity is also strongly impacted by their social world (Broderick & Blewitt, 2002, p. 314; Pruitt, 1999, p. 9). Other than siblings, influences of culture, parents, neighbours, peers, school, and historical context all play a role in adolescent identity formation. While there are many circles in which the adolescent will explore and search out information for their identity, the adolescent's peer group is often the circle that will have the strongest impact (Broderick & Blewitt, 2002, p. 315; Pruitt, 1999, p. 9). The adolescent will search out ways to understand the world by considering their peers' interests and opinions. The peer circle becomes an arena for validation and the "trying on" of different behaviours and characteristics (Broderick & Blewitt, 2002, p. 315). Peers will not only imitate one another, but become identified with one another as they gravitate towards similar interests. Information and experiences gathered from peer interactions develop the adolescent's sense of autonomy and provides them with feedback about how they interact in the world beyond their familial experience. This peer process mirrors, I think, the between-sibling processes of *identification* and *differentiation* suggested and described by Wong (2010), whereby siblings try to differentiate themselves by asserting their individuality. Siblings and peers thus contribute to the foundation and formulation of the adolescent's sense of self (Broderick & Blewitt, 2002, p. 316). Regarding my study, the impact of peer affiliation on adolescent development is, therefore, important to consider, because peer-relations can be disrupted by the cancer experience for well-siblings. For example, changes to family routines and roles can reduce opportunities for and impact the ways

in which siblings are able to engage in outside school activities and other social events (Alderfer et al., 2010). Further, siblings may struggle to relate and communicate with their peers who do not have or have not had a similar life experience of cancer in their family. Specific to this, Patterson et al. (2014) included in their *Siblings of Cancer Needs Inventory* (SCNI) several items attending to needs such as “to have time to look after myself and focus on my own needs” and “a need for my friends to understand what I am going through” (p. 656). The need for peer involvement and encouragement to participate in personal activities for well-siblings is a need previous literature has explicitly addressed (Barrera, Fleming & Khan, 2004; O’Shea et al., 2012; Patterson et al., 2011; Wilkins & Woodgate, 2005).

Both common knowledge and research describe navigating the intense growth, identity development and intricacies of adolescence as a challenging period of development. It is understandable therefore that the developmental challenges of adolescence are likely to be possibly even more, and certainly uniquely, challenging for an adolescent of a sibling living with cancer. Indeed, the cancer diagnosis itself of a sibling may influence an adolescent to reflect differently on their own identity (Alderfer et al., 2010)—and possibly even life—in both positive and negative ways.

Need Theory: A Brief and Broad Overview

Broadly speaking, need theory has its roots in the long-held philosophical quest to answer and understand questions about the human condition. These questions include those about fundamental human motivations, the directedness of human life, and the nature of human well-being. Philosophers, theologians, sociologists, psychologists, and other scientists have all explored these grand questions.

In psychological terms, needs are internal—biological, psychological, or both—forces which operate within, and as a response to, the contingencies of the internal and external environments of the individual. Through arousing and organizing human perception and behaviour in the direction of a goal, needs, at their most basic level, function to change unsatisfying situations into more satisfying situations (McAdams, 2001, p. 458). One of the first theoretical models of human motivation was Henry Murray's (1938) conceptualization of needs in the late 1930s, and psychologist Abraham Maslow proposed the widely known and oft-referred to theoretical model of needs—Maslow's Need Hierarchy—in the 1950s. Two other well-established theoretical models of needs within the counselling psychology literature are those of Ryan and Deci's self-determination theory (2000) and Glasser's choice theory (1998). Ryan and Deci (2000) described three basic psychological needs, namely the needs for competence, autonomy, and relatedness. Glasser (1998) described five basic needs: one basic physiological and psychological need for survival, and four basic psychological needs for love/belonging, power/achievement, freedom/independence, and fun. For the present purposes, because Maslow's theory and hierarchy of needs is the foundation of so much of the contemporary literature, I go on now to provide a little more information only about Maslow's conceptualization of human needs.

In a nutshell, human beings are born into the world with predetermined needs, which *need* to be fulfilled in order to survive, grow, and flourish. Maslow (1970, p. 51) described the ordering of need satisfaction as a prioritization process, a hierarchy of needs. Maslow originally articulated human needs into five distinct levels (1943), later expanding the model to an eight-

level model (1970). At the base of the original five-level hierarchical pyramid¹ are biological and physiological needs, followed by the needs for safety, love and belonging, esteem, and self-actualization. Maslow posited that a “higher” need cannot be met unless the “lower” prepotent need has been reasonably satisfied. In other words, Maslow did not mean that the prepotent need will or must be completely satisfied in order to move on. Maslow (1970) stated that we will always be partly satisfied and dissatisfied in all our basic needs (p. 52).

Of relevance to my thesis, I was interested to read that Maslow articulated the idea that when children are confronted with illness, they feel immediately threatened and unsafe.

Specifically, Maslow (1943) wrote:

Such a moment of pain, it may be postulated that, for the child, the appearance of the whole world suddenly changes from sunniness to darkness, so to speak, and becomes a place in which anything at all might happen, in which previously stable things have suddenly become unstable. (p. 377)

Maslow also laid out a set of preconditions of freedom necessary for the satisfaction of needs. He outlined these freedoms as: “freedom to do as one wishes so long as no harm is done to others, freedom to express oneself, freedom to investigate and seek for information, freedom to defend oneself, fairness, and honesty” (Maslow, 1970, p. 47). These freedoms, according to Maslow, must be achieved because without them the basic needs are unattainable or severely

¹ *Physiological needs* can be defined as the needs for air, water, food, shelter, warmth, sleep, and sex; *Safety needs*: security, law, order, routine, freedom from fear, and stability; *Belongingness and love needs*: friendship, intimacy, affection, and love from others; *Self-esteem needs*: independence, status, prestige, self-respect, respect from others, and to feel acknowledged, useful, capable and adequate; and *Self-actualization needs*: being true to one’s own nature by seeking, realizing, and living one’s true potential, authenticity (Maslow, 1970, pp. 35-46).

threatened. According to Maslow when essential needs are unattainable or prevented from being met, people develop psychological illness, or psychosocial and emotional difficulties.

I have now described my researcher location and provided a basic overview of adolescent development and need theory to give context and background for my research question, which explores the experience and needs of adolescent siblings who have a brother or sister diagnosed with and treated for cancer. Next, I give a review of the current literature with respect to: (a) statistics and definitions of childhood cancer in Canada; (b) prevalence and anecdotes of the well-sibling experience; (c) evidence and information on the psychosocial and emotional impact of a cancer diagnosis and subsequent treatment on well-siblings; and (d) the needs of well-siblings as presented in previous research. To conclude I will present my thesis objective, rationale, and research question that I answer through my research study.

Literature Review

The scope of the literature review includes journal publications, books, and websites published over the past 71 years. I utilized online databases including: PsycINFO, ERIC, CINAHL, Social Work Abstracts, SAGE Journals, Google Scholar, and Summons. As key words to search the databases, I used: *siblings*, *childhood cancer survivors*, *brothers and sisters*, *family*, and *adolescent siblings*. From this search, I found international, multi-cultural, and multi-disciplinary (including psychology, psychiatry, medicine, nursing, qualitative health research, social work, and marriage and family therapy) studies, which form the basis of this review.

Childhood Cancer

Of the total new cancer cases diagnosed in Canada in any given year, childhood (0-19 years-of-age) cancers account for less than 1% of the total cancers diagnosed (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2014). It is estimated that an average of

1,500 children and youth are newly diagnosed with cancer each year, and that another 10,000 children are already living with cancer (Childhood Cancer Canada Foundation, 2011). The Canadian Cancer Society's Advisory Committee on Cancer Statistics asserts that while cancer in children and youth is rare, it "has a significant impact on these children and their families" (2014, p. 29). It is also indicated that while childhood cancer incidence rates have been constant since 1985 the survival rate continues to increase, a point of interest for me as a researcher because I chose to focus on well-siblings whose sibling survived cancer, rather than to focus on bereaved siblings.

Between 2006 and 2010, the most commonly diagnosed childhood cancer was Leukemia, which accounted for 32% of all newly diagnosed cases (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2014). The committee stated that other commonly diagnosed cancers for children were cancers of the central nervous system and lymphomas (19% and 11% respectively) (p. 29). While these cancers affect different parts of the body, one feature they share in common is that the treatment course is often arduous, invasive, and treacherous for the sick child (Patterson, Holm & Gurney, 2004). The treatments on the sick child leave physical and emotional evidence of the pain they endure, while the emotional impact on the sibling who witnesses this pain (Prchal & Landolt, 2012) can be difficult to identify and see.

Siblings of Children with Cancer: Prevalence, SuperSibs! and Anecdote

As I noted at the outset, according to Childhood Cancer Canada, there are approximately 10,000 children living with cancer today in Canada, and approximately 1,500 new cases are diagnosed yearly (Childhood Cancer Canada Foundation, 2011). Statistics Canada (2013) cited that in 2011 for every Canadian family there were approximately 1.8 children. Assuming that each child diagnosed with cancer represents one family, then it can be approximated that 1,200 well-

siblings ([1,500 families x 1.8] - 1,500 children diagnosed with cancer) had a brother or sister diagnosed with cancer in 2011, and that there are approximately 8,000 siblings ([10,000 families x 1.8] - 10,000 children living with cancer) of children living with cancer today in Canada. It has been reported that nearly 65% of well-siblings experience some sort of psychological problem following the diagnosis of their sibling (Sahler et al., 1997 as cited in Barrera et al., 2002). This means that roughly 780 of the 1,200 well-siblings of the 1,500 children diagnosed with cancer every year, and approximately 5,200 of the 8,000 well-siblings of children living with cancer, are likely to experience some type of psychological distress at some point. If Sahler et al.'s (1997) group are correct in their finding that almost three quarters of well-siblings are likely to experience some sort of psychological problem, then one explanation might be that well-siblings have needs that are not being met, either reliably or adequately, leaving well-siblings asking, "What about me?" (Murray, 1998; Prchal & Landolt, 2012).

SuperSibs! I thought it was important to make mention of the online resource and organization SuperSibs. SuperSibs is a program for well and bereaved siblings aged 4-18 years old that is a part of Alex's Lemonade Stand, an American not-for-profit organization providing support and recognition to children with childhood cancer. SuperSibs was created in 2003 by Melanie Goldish, a mother whose child lived through cancer, and who witnessed the impact the cancer diagnosis had on her well son. SuperSibs offers a place for siblings to explore and hear from other children and youth who have gone through similar experiences. The organization mails support tools from their Comfort and Care program to siblings and their parents. Tools include guides, tokens of recognition, cards and age-specific newsletters to recognize and celebrate siblings, along with information for their parents, and resources, helpful tips, and coping tools for supporting the well-sibling. The SuperSibs website not only offers information

and support to the well or bereaved siblings, but also to the people in their lives like parents, guardians, extended family, friends, and teachers. The services are provided for free, and though they are based in the U.S., they also provide support to children in Canada.

The only research I found about the effectiveness of the *SuperSibs* program was an independent study completed by Lanin-Kettering and Malone (n.d). In this research study, data were gathered qualitatively through focus groups ($n=6$) which were comprised of 45 participants in total. The groups were made up of well-siblings (aged 7-16), parents and bereaved siblings. In the quantitative study ($n=432$) participants received 3 separate surveys (parents $n=291$; children ages 7-11, $n=95$; and teens/tweens ages 12-18, $n=46$). The findings from the focus groups reported that the Comfort and Care interventions offered by *SuperSibs* made a positive difference in the lives of the well and bereaved siblings along with their parents. The quantitative data reported that 75% of the respondents felt stronger and more hopeful after receiving support from *SuperSibs*' Comfort and Care services over a period of 1-4 years. In my evaluation of their program it appears that they are providing integral, holistic, informative support for well-siblings and their family members. To strengthen the program evaluation *SuperSibs* might consider longitudinal exploratory studies where they can measure the impact of their services from a before and after standpoint.

Anecdote. The need for siblings to be considered in the cancer equation is the issue at the heart of what has led me to this research. For the summers of 2010 and 2011, as I mentioned in my researcher location, I worked as the participant support supervisor for the Canadian Cancer Society's summer camp, *Camp Goodtimes*. *Camp Goodtimes* is an oncology summer camp for children diagnosed with cancer and their family members. Sick children are allowed to bring their siblings to camp with them, so that both the sick and well-siblings are able to benefit from

the internationally acclaimed summer recreation program (Campgoodtimes, 2011). As part of camp activities that included, for example, swimming and arts and crafts, there were social-support activities for which I was a group leader. The sharing circles aimed to facilitate a safe and inclusive environment for the campers to share their joys, hopes, fears, and pain about their individual experience with cancer. In one particular sharing circle I heard the voice of a sibling Sarah² choking on her words as she expressed her frustration: “They always ask me how Joey is...I just wish they would ask me how I am!” Her words came flying out with tears of sadness and anger, and the sentiment rippled around the sharing circle. Quickly sick campers throughout the room shared how they had never considered how their cancer experience impacted their well-siblings, and some well-siblings shared their hurt and experience of feeling left out. Some of the sick campers were currently undergoing cancer treatment and others were several years past their cancer diagnosis with treatment complete. Regardless of where the youth were in their cancer journey², there was a flurry of discussion as the sick and well-siblings reflected on that turbulent time and questioned its impact. It was apparent the discussion was one that many youth in this large group of about 30 campers, ranging between the ages of 12 to 18, had never had.

Sarah’s lament that “They always ask me how Joey is...I just wish they would ask me how I am!” is precisely what Murray (1998) and Prchal and Landolt (2012) noted: that well-siblings repeatedly report having to answer the question “How is your sibling?” when really, what they desperately wish someone would ask them is, “How are you?” This anecdotal and empirical evidence supports the sentiment of Wilkins and Woodgate (2005): Siblings of children with cancer need to have their voices heard.

² All names and identifying demographics in the anecdotes have been changed for anonymity.

Anecdotal reports and empirical findings suggest well-siblings are left out of the cancer equation to lesser or greater degree; I believe this can be considered understandable given that these situations involve a family member with a life-threatening illness. Yet, I suggest too that we consider it also understandable and necessary for well-siblings to have their voices heard and needs met. Supporting siblings to have their voices heard and needs met will benefit the overall family's wellbeing and the well-sibling's ability to cope with the cancer diagnosis (DiGallo, 2003; McCubbin, Balling, Possin, Frierfich & Bryne, 2002). What adolescent-age well-siblings need and how best to support them in having their voices heard and needs met, are precisely the answers I aimed to uncover in my research.

Evidence: Psychosocial and Emotional Impacts and Outcomes of Cancer on Well-Siblings

In their qualitative review of the literature, Wilkins and Woodgate (2005) presented three major themes they identified through their review of 27 studies looking at the well-sibling experience (ages ranged from 5 to 40 years) of the childhood cancer experience. These three overarching themes of the sibling experience of childhood cancer were: (a) changing lives, (b) intense feelings, and (c) unmet needs.

Changing lives was the most prevalent theme that arose across the 27 studies reviewed by Wilkins and Woodgate (2005). Within the theme of changing lives were two subthemes: losses and gains. Losses encompassed strains on parent and child relationships, perceived preferential treatment of the sick child, increased sibling rivalry, and an experience of loss of sense of self. Gains included: family cohesion, positive support from others, increased compassion and empathy, and development of independence and responsibility. Some siblings also reported an increased appreciation for the fragility of life, a finding supported by Murray (1998) and also recently confirmed by Malone and Price (2012), who cited the findings of Havermans and Elser

(1994), Heffernan and Zanelli (1997), and Sloper (2000). Two quotes from siblings in two different studies will help to illustrate what is meant by an increased appreciation for the fragility of life. In Murray's (1998) single-case qualitative study, the 14-year-old sibling said: "I learned something valuable from watching life struggle against death. I learned that peace is everywhere, even in the time of deepest trouble...There is a good and bad to everything in life" (p. 223).

Similarly, Lehna (1998) reported the following statement from a 22-year-old sibling who reflected on her experience; the sibling was 8-years-old when her 6-year-old sister was diagnosed with leukemia:

And we would get in these big, long, involved discussions about death and how I'm not afraid of it anymore. It doesn't...scare me. It's a part of life. And death is always a part of life...I don't want to die when I'm 22, and I don't want to die when I'm, you know whatever, but seeing my sister and, I guess, how close to death she could have come...Life [is] short and you should take advantage of everything that comes your way, and you can't prevent death. (p. 169)

In their study assessing psychological changes experienced in the aftermath of a traumatic or highly challenging event, Kamibeppu et al. (2010) defined these types of "gains" that Wilkins and Woodgate describe, as *post traumatic growth*. (The study compared cancer survivors ($n = 185$) and their well-siblings ($n = 72$), against a control group ($n = 1000$) with no history of cancer in self or family, 658 of whom reported a history of trauma.)

Regarding their second theme—*intense feelings*—Wilkins and Woodgate (2005) confirmed that the well-sibling's experience is an emotional and a potent one. Siblings experience the heights of the gains, and the depths of the losses: an emotional rollercoaster at times. The emotional intensity of the well-sibling experience sees siblings overwhelmed by

complex feelings of sadness, fear, loneliness, rejection, jealousy, anger, anxiety, and guilt. An example of these complex feelings was captured by a well-sibling's anecdote in Lehna's study (1998), "I just remember being really scared, that I wanted to cry, but I didn't want to cry in front of her [sick-sibling]; I wanted to be strong for S [sibling]" (p. 166).

Contributing to the intensity of well-siblings' feelings is the very fact that, for most people, the word cancer is synonymous with death, leaving many well-siblings wondering if their brother or sister will survive (Prchal & Landolt, 2012). One well-sibling in Lehna's (1998) study expressed the range of emotions she experienced when considering her sister's possible death: "I was very terrified because she was my *little* sister, and little sisters outlive big sisters" (p.168). Learning to what Wilkins and Woodgate would describe as a "gain," watching her sibling come through cancer shaped this well-sibling's relationship with death. Siblings who acknowledged their fear of death showed up sporadically throughout my review of the literature. Well-siblings reported different emotions and thoughts regarding death, with some reflecting a new appreciation for the fragility of life (Lehna, 1998; Murray, 1998; Wilkins & Woodgate, 2005), and others reporting their general fear upon first hearing the diagnosis (Lehna, 1998; O'Shea et al., 2012; Woodgate, 2006). If support is provided to share in this dialogue of their fears and emotions, and if information is given regarding their siblings' illness, it is believed that some of these anxieties can possibly be reduced (Breyer, Kunin, Kalish, & Patenaude, 1993).

Wilkins and Woodgate (2005) noted that while society might have a tendency to judge the intense feelings of well-siblings as problematic, they asserted that siblings are often responding in healthy and normal ways to an incredibly difficult experience. Breyer et al. (1993) stated that well-siblings who are encouraged to access and directly express their anxiety, worries, and fears, and who are included in their sick-siblings' care, are more likely to adapt positively to

the strains and stressors of having a sibling with cancer. In general clinical practice for all human conditions and experiences, Greenberg (2004) supported the “usefulness” of so-called negative emotions such as anxiety. He suggested that when intense emotions such as anxiety, sorrow, and anger are met with skills that allow the person to become aware of the emotions, they can learn to tolerate the feelings and so become able to regulate themselves after the experience. Wilkins and Woodgate (2005) suggested that well-siblings need to be encouraged and supported to experience these emotions in order to have specific needs met (the third major theme which I will address next). Further they contended, “the multitude of feelings experienced by siblings suggests the need for appropriate social support services that are grounded in research and are from the perspective of siblings” (Wilkins & Woodgate, 2005, p. 314). By feeling supported and safe in their emotional experience, siblings’ turmoil and upheaval is not only justified, but also made just as valid as all other family members’ experiences. As one sibling said: “cancer is very painful inside...very sad” (Woodgate, 2006, p.411). Cancer is a painful diagnosis for all people impacted by its presence, both physically and emotionally.

Unmet needs was the third theme Wilkins and Woodgate (2005) identified. Siblings reported needs for the following: (a) need for information about the cancer diagnosis and treatment; (b) need for involvement in caring for their sick-sibling; (c) need to be supported to maintain own interests and activities; and (d) need for family communication. Wilkins and Woodgate (2005) suggested that these needs must be attended to in order to provide adequate psychosocial support for siblings. Patterson et al. (2011) and O’Shea et al. (2012) echoed the importance of attending to the unmet needs of well-siblings.

There are at least five explanations I have derived from the literature for the psychosocial and emotional impacts and outcomes of cancer on well-siblings. One explanation is the news of a

sibling's cancer diagnosis and the experience of living with a sibling with cancer, include intense feelings (Lehna, 1998; Wilkins & Woodgate, 2005) and uncomfortable emotions such as: depression, anger, anxiety, fear, jealousy, feelings of guilt, and social isolation (Alderfer et al., 2010; Lehna, 1998; Murray, 1998; Patterson et al., 2011). Furthermore, well-siblings of all ages across these studies were found to have had an inclination to internalize their emotions due to: (a) not wanting to be a burden on parents who are already distressed and heavily laden with responsibility, or (b) holding a perception that their own problems are insignificant in comparison to those of the diagnosed child (Prchal & Landolt, 2012; Vermaes, Susante, & Bakel, 2010; Wilkins & Woodgate, 2005; Woodgate, 2006).

A second explanation is the change/s to the sibling relationship. When a sibling is diagnosed with a potentially life-threatening or life-altering sickness such as cancer, a disruption occurs in the sibling relationship. This grave news heightens the intensity of normative feelings, tensions, and interactions between siblings (Breyer et al., 1993).

A third explanation lies in how the well-sibling responds and adjusts to changes within their family structure and functioning. Examples of these changes are: changes to familial roles, schedules, and routines; the disruption of emotional stability; decreases in parent-child interactions; and increased overall emotional stress and changes in the family home and family dynamics as everyone tries to cope with the reality of having a sick family member (O'Shea et al., 2012; Patterson et al., 2011; Wilkins & Woodgate, 2005; Woodgate, 2006). Changes in roles can sometimes look like the well-sibling taking on more care-taking responsibilities within the family, or what Hooper (2012) refers to as the "parentified child" (a child who experiences a disturbance of generational boundaries that causes the child to take on role reversals in either or both, functional and emotional roles). The fallout from all of these changes may, for some

siblings, result in long-term consequences such as cancer related post-traumatic-stress reactions (Kaplan, Kaal, Bradley & Alderfer, 2013). Interestingly, in some studies the age of the well-sibling might be related to how s/he responds and adjusts to these changes. Houtzager et al. (2005) reported that, when compared to their peers, older siblings of children diagnosed with cancer were found to have a lower quality of life in areas of cognitive ability and positive emotions. With increasing age, siblings reported significantly more challenging emotions, and Houtzager et al. (2005) claimed adolescent-aged siblings appeared to be more vulnerable for a negative mood compared to same-aged peers not affected by cancer. Further, there may be an interaction between age and gender in how the well-sibling responds and adjusts to the sick-sibling's diagnosis and cancer treatments, and to the ensuing changes within their family structure and functioning (Alderfer et al., 2010; Houtzager et al., 2005). In Alderfer et al.'s (2010) review of the literature they found 8 studies that looked at gender and its relation to adjustment, and from these 8 studies reported that female well-siblings tend to report a higher degree of distress than males. Houtzager et al. (2005) reported that female well-siblings reported greater levels of post-traumatic stress, anxiety, and social problems than male well-siblings; older sisters were also significantly less satisfied with relationships with family members, peers, and others. Older female siblings might also be at greater risk due to the gendered implications of the female caretaker role (Alderfer et al., 2010; McGoldrick et al., 2005, p. 156). For example, Houtzager et al. (2005) reported that female siblings often take on more household responsibilities, which impacts their ability to spend time with friends and engage in social activities. Additionally, the role of peer relationships is a confound of age. As noted earlier, peer relationship satisfaction plays a figural role in adolescent social development and identity development (Broderick & Blewitt, 2002, p. 314; Pruitt, 1999, p. 9). However, many of the

studies informative to the understanding of the well-sibling's experience are from heterogeneous samples making it difficult to distinguish and tease out age-related correlates and patterns of responses among adolescent well-siblings to changes within the family structure and functioning, as a function of a sibling's cancer diagnosis and treatment.

A fourth explanation involves the presence and impact of social support in the lives of well-siblings on their response and adjustment (Alderfer & Hodges, 2010). Barrera et al. (2004) reported that siblings (regardless of age or gender) who were provided with high social support had fewer behaviour problems and symptoms of depression and anxiety. Social support is the belief that a person holds about their worth in relation to the people in their social circles; namely it is the belief that they matter and are valued within their social network (Alderfer & Hodges, 2010). As such, the perceived receipt of social support results in "feelings of attachment, security, being loved, being part of a group, reassurance of self-worth, availability of information, emotional and material help" (Barrera et al., 2004, p.104).

A fifth explanation attempts to link the responses and adjustment of well-siblings to the degree to which their individual needs are met (O'Shea et al., 2012; Patterson et al., 2011; Wilkins & Woodgate, 2005). In their mixed-design study of unmet needs reported by well-siblings aged 12-24 years, Patterson et al. (2011) for example, found a positive and significant relationship between unmet needs and higher levels of difficulties with psychological functioning in adolescents aged 12-17 years. The inability or unwillingness to share their emotional stress (Prchal & Landolt, 2012; Vermaes et al., 2010; Wilkins & Woodgate, 2005; Woodgate, 2006) as noted earlier, causes greater anxiety within well-siblings, heightening their needs for attention, love, and belonging; needs that sometimes go unmet during times of trauma

(Woodgate, 2006). The issue of the needs of siblings is the focus of my study, and I discuss such in the following section.

Psychosocial and Emotional Needs of Siblings

Siblings of children with cancer typically experience challenges with getting their needs met (Ballard, 2004; Murray, 1998; O'Shea et al., 2012; Patterson et al., 2011; Wilkins & Woodgate, 2005; Woodgate, 2006). Two studies are particularly informative about the needs of siblings of children with cancer: the O'Shea et al. (2012) study that surveyed paediatric oncology nurses for their perspective on the needs of siblings; and the Patterson et al. (2011) study reporting the development and piloting of a needs-based measure, the Sibling Cancer Needs Instrument (SCNI) as noted previously which has been further validated by Patterson et al. (2014).

O'Shea et al. (2012) noted the recent shift in cancer research from focusing on bereaved siblings to focusing on siblings' psychosocial and emotional needs. This is likely due to the increased survivorship amongst children diagnosed with cancer. In a qualitative study of 13 paediatric oncology nurses, O'Shea et al. (2012) outlined the needs of siblings through the eyes of nurses who worked with families of children who had lived through cancer. Overall, nurses expressed that needs of siblings were not often as well attended to as previous literature had suggested. From their analysis of the data, O'Shea et al. identified the following four needs of well-siblings: (a) wanting and "getting" attention—possibly as a result of feeling jealous and left out; (b) wanting to know—siblings wanted to understand their sibling's illness; (c) wanting to help—siblings wanted to help care for their sick-sibling; and (d) wanting a normal routine (pp. 224-225). The nurses' reported divergent views as to whose role it was to fill and support these needs. Some saw their role as a nurse as a minor role within the family's experience. These

nurses saw their role as mainly to support the parent so parents could attend to the needs of their children. However, other nurse participants had what they called a “holistic approach,” attesting that their unit had a philosophy of attending to the needs of the whole family (p. 226). Overall however, O’Shea et al. (2012) reported that regardless of how much nurses could support the family’s needs, it was ultimately the job of the parents to fulfill and satisfy the needs of the well-siblings.

The Patterson et al. (2011) study also looked specifically at siblings’ needs, but from the sibling perspective. In their 2011 study where they developed the SCNI, Patterson’s group conducted a focus group ($n=4$) and qualitative telephone interviews with well-siblings ($n=7$), and gathered data from staff members ($n=57$) who worked with well-siblings. Participants in the focus group and telephone interviews, were asked the question: “What were/are the most important unmet needs from your experience with cancer?” and they were asked whether these were past or current needs (p. 18). The staff were sent a survey on which they were asked to list “up to five important needs that you think young people between the ages of 12 and 24 with a brother or sister with cancer have” (p. 18). From the initial qualitative interviews, Patterson’s group identified the following 10 need domains: (a) peer support (friends); (b) peer support (similar experience); (c) information; (d) sibling relationship and support; (e) expressing and coping with feelings; (f) respite and recreation; (g) acknowledgement and attention for self; (h) involvement in the cancer experience; (i) instrumental support; and (j) access to support services and professional help. To create the SCNI the need domains were then distilled into 80 question items that were considered to represent these initial 10 domains. An example of an item is coping with added family stress, which goes under the domain of “access to support”; another example of an item is spending time with peers who have gone through a similar experience, which falls

under the domain of “peer support (similar experience)” (p.23).

Participants in the 2011 quantitative-arm of the study completed a demographic survey, the SCNI, and a psychological functioning measure. Participants were 71 well-siblings (aged 12-24 years, $M = 16.6$ years, $SD = 3.6$) with a sibling diagnosed with cancer in the last 5 years. Of these well-siblings, 90% reported having at least one unmet need during their sibling’s illness. Further, more than 70% of the well-sibling participants also indicated that they had a current unmet need. The limitations of the SCNI were stated as: (a) convenience sampling from one peer support organization; (b) a long time-frame for responses (in the last 12 months); and (c) complex response options making responding difficult for participants.

In 2014 Patterson and a new team of researchers assessed the psychometric properties of the SCNI and attended to the limitations of the 2011 survey. A sample of 106 well-siblings (between the ages of 12-24 years who had a brother or sister [of any age] diagnosed with cancer within the last 5 years) completed the SCNI, which contained 73 of the original items from the 2011 creation of the SCNI. Respondents completed a demographic questionnaire, the SCNI, and the Kessler 10 (K10) (a 10 item measure used to measure psychological distress, which Kamibeppu et al., 2010 also used). Results were then validated through exploring the correlations between the SCNI and psychological distress as measured by the K10. Patterson et al. reported internal consistency and test-retest reliability, as well as construct validity as shown through the correlations between the K10 and the SCNI, which allowed for the removal of problematic and redundant items from the 2011 survey. The final SCNI was distilled to 45 item questions and 7 domains, which are the needs for: (a) information about my sibling’s cancer; (b) “time out” and recreation; (c) practical assistance; (d) support from my friends and other young people; (e) dealing with feelings; (f) understanding from my family; and (g) my relationship with

my sibling with cancer. Patterson et al. contended they have created an important and valid tool for helping to assess and support the psychosocial needs and unmet needs of well-siblings. They endorsed the importance of creating a self-report measure because parents are often found to underestimate the impact of the cancer diagnosis on siblings.

Interestingly, the 4 needs identified by O'Shea et al. (2012) and the 7 need domains of the SCNI by Patterson et al. (2014) correspond closely with Wilkins and Woodgate's (2005) third theme "unmet needs" that came from their review of 27 qualitative studies on the experience of well-siblings. I chose to contrast the studies by Patterson et al. (2014) and O'Shea et al. (2012) against Wilkins and Woodgate's review because, at present, their meta-review is the largest amalgamation of previous research considering the needs of well-siblings. (See Table 1 for an overview of the three studies).

Table 1.

Three Studies that Reported on the Needs of Well-Siblings

Researchers	Population	Study Design/ Method	Findings: Identification of Need for:
Wilkins & Woodgate (2005)	Samples included well-siblings across the age range of 5-40 years of age. Bereaved and non-bereaved siblings.	Meta-analysis of 27 qualitative studies.	<ol style="list-style-type: none"> 1. Information about the cancer diagnosis and treatment 2. Involvement in caring for their sick-sibling 3. Support to maintain own interests and activities 4. Need for family communication
O'Shea, Shea, Robert & Cavanaugh (2012)	13 paediatric oncology nurses.	Qualitative descriptive study, using semi structured interviews.	<ol style="list-style-type: none"> 1. Wanting attention 2. Wanting to know 3. Wanting to help 4. Wanting a normal routine
Patterson et al. (2014)	106 siblings between the ages of 12-24 years of age who had a living brother or sister (of any age) diagnosed with cancer within the last 5 years.	Quantitative exploratory factor analysis of Sibling Cancer Need Instrument (SCNI) using Rasch analysis.	<ol style="list-style-type: none"> 1. Information about my sibling's cancer 2. "Time out" and recreation 3. Practical assistance 4. Support from my friends and other young people 5. Dealing with feelings 6. Understanding from my family 7. My relationship with my sibling with cancer

By considering the operational definitions of the needs identified by the authors for their respective studies, I think there are some clear, and helpful, conceptual overlaps and points of synthesis to point out. To remind the reader, Wilkins and Woodgate (2005) identified 3 themes in their investigation of the experience of well-siblings: (a) Changing lives; (b) Intense feelings; and (c) Unmet needs. Of the needs identified by Wilkins and Woodgate within their third theme *Unmet needs*, 3 of their 4 needs overlap with the 4 needs identified by the nurses in the O'Shea et al. (2012) study: (a) *Information about the cancer diagnosis and treatment* overlaps with *Wanting to know*; (b) *Involvement in the caring for their sick-sibling* with *Wanting to help*; and (c) *Support to maintain own interests and activities* with *Wanting a normal routine*. Interestingly, Wilkins and Woodgate's 4 needs appear to overarch 6 of the 7 needs determined by Patterson et al. (2014): (a) Wilkins and Woodgate's identified need for *information about the cancer diagnosis and treatment* (and similarly, O'Shea's *Wanting to know*) overarches the Patterson group's need for *information about my sibling's cancer*; (b) *Involvement in the caring for their sick-sibling* (and O'Shea's *Wanting to help*) overarch *My relationship with my sibling with cancer* and *Understanding from my family*; (c) *Need for family communication* overarches *Understanding from my family* (which can be related to O'Shea's *Wanting attention*); and (d) *Support to maintain own interests and activities* (O'Shea's *Wanting a normal routine*) overarches *Time out and recreation*, *Support from my friends and other young people*, and *Practical assistance*.

I think it is important to elaborate on the last mentioned set of interrelated needs identified among the 3 studies. Upon first glance, it could appear that the need for *practical assistance* (Patterson et al., 2014) does not correspond with Wilkins and Woodgate's (2005) need for *support to maintain own interests and activities*. However, Wilkins and Woodgate

included in the *need for support to maintain own interests and activities* items such as, being given “assistance with important day-to-day tasks (e.g., transportation to school, attending support groups)” (p. 656) and the importance for siblings to be a part of support groups and for being given support in general terms. Patterson et al. described the *need for practical assistance* as being given help with household duties, educational pursuits and schoolwork duties, transportation, work responsibilities, and having access to professional support services—all tasks which fit under the Wilkins and Woodgate need for *support to maintain own interests and activities*.

I will now explain the needs identified by both the O’Shea (2012) and Patterson (2014) groups that I believe do not fit within Wilkins and Woodgate’s (2005) summation of well-siblings’ needs. It might be that *Wanting attention* as the nurses in the O’Shea group’s study viewed the need for attention, is reflected or captured within and across the 3 themes labelled by Wilkins and Woodgate as *changing lives*, *intense feelings*, and *unmet needs*. For example, under the umbrella of Wilkins and Woodgate’s first theme of *changing lives*, the need for attention is identifiable under the subtheme of *losses* in which siblings experienced a loss of time spent with their parents, and under the second theme of *intense feelings* which referred to and reflected emotions such as sadness, loneliness, and rejection from changes to parental involvement in their lives.

The need for attention is also recognizable in two of Wilkins and Woodgate’s (2005) 4 subthemes of needs comprising their third theme *Unmet needs*—namely, the needs for *family communication* and for *involvement in caring for their sick-sibling*. I suggest that the *need for family communication* and, most especially, for open and honest communication with parents, might indirectly reflect the needs for both attention and for information. Wilkins and Woodgate

also articulated that siblings who were not involved with the sick child's care felt left out and abandoned, possibly implying, therefore, the need for attention. Interestingly, in a separate study, Woodgate (2006) spoke directly about and provided supporting quotes to illustrate well-siblings' desire and need for attention. For example, when one sibling was asked what advice they would give to parents, the participant said: "I would say that parents should pay a little more attention than what they would usually pay to us. Like how they are right now because then maybe their other child who is not sick would not feel left out" (p. 411).

Like O'Shea et al.'s (2012) identified need *Wanting attention*, there appeared to be one need from the Patterson et al. (2014) study that did not fit within the unmet needs proposed by Wilkins and Woodgate (2005), this was: *Dealing with feelings*. I believe the need for dealing with feelings is reflected in the other 2 themes presented by Wilkins and Woodgate, *changing lives* and—most specifically—*intense feelings*. Wilkins and Woodgate validated the presence of changing lives and intense feelings, and Patterson et al. described well-siblings' need for support to find ways to express how and what they feel about their sibling's cancer. Along with knowing how and what they feel, well-siblings needed to find ways to "deal" (Patterson et al.) with the gains, losses, and intense feelings associated with their changing lives.

To draw this section together, I have worked to amalgamate the findings of Patterson et al. (2014), O'Shea et al. (2012), Wilkins and Woodgate (2005; 2006), and also DiGallo (2003), into 5 overarching categories of the needs of well-siblings. I will describe and discuss these in greater detail by using other literature and anecdotal reports as triangulation. The 5 overarching categories of needs that were apparent to me in my review of the literature are: (a) the need for attention; (b) the need for involvement in the care of the sick-sibling; (c) the need for support,

routine, and continuity in personal interests and activities; (d) the need for support in understanding and expressing intense emotions; and (e) the need for family communication.

(a). Need for Attention. While younger siblings had more difficulty understanding the reasons for the lack of parental attention, adolescent siblings reported a broader awareness of why their parents' attention was directed elsewhere, but still struggled with this reality (Bendor, 1990; Wilkins & Woodgate, 2005). In Murray's (1998) study one 14-year-old sibling's need for attention was illustrated when they said: "I began to feel hatred for my sister. I often thought if I got sick, maybe I too would receive presents and sympathy. My sister stood bathed in the spotlight, and I'd been thrown in the corner" (p. 222). Parents feel pushed to make challenging decisions of who to spend their time with, when, and how much—decisions many parents struggle and suffer with—and often the decision is to be with the sick child (O'Shea et al., 2012).

I think it is important to note the finding by Woodgate (2006) that well-siblings who had the opportunity to spend time alone with their parents, regardless of the activity or duration, reported less feelings of loneliness when subsequently their parents had to be away from them. Woodgate articulated that siblings described a desire for being with and spending time with their parents and their sick-sibling. Being with parents supports the need for attention, a need which siblings in Woodgate's study dismissed as often "unrealistic" due to their sick-sibling's illness. One sibling, when asked what parents could do, reported, "If parents could maybe try and take us out like just every once in a while. Just so the parents and siblings can actually see what is going on" (Woodgate, p. 411). In the Patterson et al. (2014) needs inventory, there are several items from the need category of *understanding from my family* that speak to a need for attention and to spend time with parents. These items are: "For my family to acknowledge that this is happening to me too"; "To be treated as a member of the family rather than as a "bystander"; "To know my

parent/s haven't forgotten about me"; "To be able to spend time with my parent/s—just me and them"; "To be noticed and have some of the attention from my family members"; and "To feel that I am just as important and valued as my sibling with cancer" (p. 657).

A 13-year old well-sibling in DiGallo's (2003) study expressed feelings of resentment towards her sick-sibling. She shared a wondering of where she fit within her family because of her role of taking care of her other well-sibling, but how during the time she chose not to express these feelings:

There was a phase during which I thought my parents had just forgotten about me, only Frances [sick-sibling] and my little [well] brother counted. He's a baby, and she's really ill. I thought to myself, 'Hey, I'm still here, but I never really said anything'. (p. 496).

(b). The Need for Involvement in the Care of the Sick-sibling. From the research, it seems that long-term adjustment for the well child is predicated, in part, on the child's inclusion in the cancer experience (Breyer et al., 1993). The sibling relationship is reported to be important for both sick and well-siblings, and well-siblings' need for inclusion and involvement often includes wanting to be actively involved in their siblings' cancer treatment and care (Breyer et al., 1993). Patterson et al. (2014) have identified this need in the domain: *my relationship with my sibling with cancer*, which speaks to siblings' need to be involved with their sick-sibling during their treatment. Under this domain are items such as: "help with understanding how my sibling is feeling"; "to be able to spend more time with my sibling while they are in the hospital"; "to know ways of giving emotional [and practical] support to my sibling"; and "to feel included in my sibling's cancer experience" (p. 657). One nurse in the study by O'Shea et al. (2012) reported the need to find a role for siblings, "sometimes just having the sibling here...to kind of help, to interact with them [the patient], and to give them company is a huge thing..." (p. 224). A

13-year old well-sibling in DiGallo's (2003) study described her experience of watching her sick-sibling vomiting:

...I wished I could do something. But I felt helpless. I never told her that I wanted to help and that I was really sorry for her. Now I think it's a shame that she sometimes thinks that I didn't care, I wasn't bothered. If I'd said something about it while she was ill, then maybe it wouldn't be like this now. (p. 496)

The need to help or to be directly involved in the care of a sick-sibling is thus one avenue for meeting the need for involvement. However, and as noted by O'Shea et al. (2012), the medical system tends to work against the involvement of well-siblings. This is partially due to hospital policies such as unit restrictions enforcing age requirements or quarantines during viral outbreaks. In the O'Shea et al. study, it was rather the case that some parents believed it was better to protect siblings from the reality and experience of the sick child; thereby leaving well-siblings out of the hospital and medical professionals bound to respecting the wishes of the parents. O'Shea et al. suggested that active involvement in the care of a sick-sibling is particularly helpful for older siblings, predominantly adolescents. Yet, as already noted, parents may attempt to safeguard the well-sibling by preventing or limiting this child's involvement in aspects of the cancer experience such as caregiving roles. On the other hand, well-siblings (ages 6-21) in Woodgate's (2006) study specifically voiced a need to "be there" for their sick-sibling. Siblings expressed a feeling of contentment in knowing that they could do something to ease their sick-sibling's suffering, and help them feel better. Conversely, well-siblings not involved in the care of their sick-sibling reported feeling guilty and bad that they could not help their sick-sibling, and wished that they could have been more actively supportive in their care.

Geographical distance could also contribute to the complexity and stress of having well-siblings involved in the care of their sick-sibling due to location of treatments (e.g., children in BC are almost exclusively treated for cancer at BC Children's Hospital in Vancouver). Finding appropriate accommodation for the whole family can be a stressor both emotionally and financially (Daniel, Wakefield, Ryan, Fleming, Levett, & Cohn, 2013). Because of the stress and chaos of the illness, well-siblings are often (and understandably so) taken care of by other family members, which increases their distance from their parent(s) and sick-sibling. O'Shea et al. (2012) warn that, "on a prolonged basis, the distancing can destroy bonds and impair relationships so that the siblings end up losing connections with the patient, their parents, and other family members" (p.225). Therefore, it appears to be imperative for the well-sibling to at least have some involvement and voice in what role they take in their sibling's illness. This role may include the care of, caring for, tending to, or companionship of their sick-sibling in the hospital and at home. Of course, it will require the support of medical personnel and parental endorsement to get and keep well-siblings involved in the caring of their sick-sibling during hospitalization (O'Shea et al.). I suggest that involvement might look like activities like company-keeping, such as watching movies or playing games, or more specific caregiving activities such as helping by providing gentle mouth swabs to ease a sibling's dry mouth. In terms of geographical distance, it may require creativity on behalf of the relocated family to come up with ways for well-siblings to still be included if it is not financially or logistically possible for the well-sibling to be away from home or school during treatments. The *SuperSibs!* website (2015) offers a document entitled "P.S.— I love you!: Patient to Sibling—I love you!" in which they outline a handful of ways that siblings can stay connected with one another. Examples of these are: telephone or Skype dates, mailing packages, reading stories together over

Skype, and taking videos or pictures of the sick-sibling's room and do the same for what is going on at home to keep them connected (SuperSibs, 2015). In the Lehna (1998) case study, for example, the well-sibling was actively involved in her sister's treatment and care. The well-sibling reported memories of holding her little sister's hand in the middle of the night to support her while she was sick from the nausea of chemotherapy. In her retrospective interview as an adult, the well-sibling reported that the experience helped strengthen her relationship with her sister.

(c). The Need for Support, Routine and Continuity in Personal Interests and Activities. O'Shea et al. (2012) operationalized their theme of *want for a normal routine* as the need for parents to keep well-siblings involved in their routine extracurricular (including social) activities. Similarly, Wilkins and Woodgate (2005) spoke to the need to maintain well-siblings' activities and interests. Patterson et al. (2014) had 3 need-domains that fit within this heading which are: "*time out*" and *recreation*; *practical assistance*; and *support from friends and other young people* (p. 656). DiGallo (2003) found that well-siblings' continued involvement in life outside of the home and school was often disrupted, and illustrated this with an example of a 13-year-old well-sibling who described how she had to forego outings and involvement with her friends to take care of her younger brother while her sick-sister was in treatment. Items articulated by Patterson et al. in the SCNI that speak to this anecdotal experience are "the need to spend more time with my friends" and to "be able to have fun" under the need-domain of "*time out*" and *recreation* (p. 656).

O'Shea et al. (2012) acknowledged keeping well-siblings connected to their personal interests and friendships was a difficult task for parents due to a large proportion of their time being devoted to their sick child. Wilkins and Woodgate (2005) reported their view that

continuing to engage in extracurricular activities and peer involvement is an important support and resource for well-siblings' ability to cope. The nurses in the O'Shea group's study also voiced a similar view that supporting well-siblings' lives and encouraging them to continue in their regular routines would help to foster feelings of stability.

Interestingly, nurses in the O'Shea et al. (2012) study reported the observation that adolescent well-siblings, when compared to their younger counterparts, expressed a greater concern of the impact cancer had on their social life and how it was making them "different" than other kids their age. Patterson et al. (2014) echoed this sentiment in their item: the need to "feel like a 'normal' young person, which it seems I've lost as a result of my sibling's cancer" (under the need-domain of "*time out*" and *recreation*), and also the item: "help dealing with being left out by my friends" (under the need-domain of *support from my friends and other young people*) (p. 656). This observation might sound self-involved to some but, when viewed from the eyes of the often self-conscious adolescent who is looking for ways to belong with peers, not to be different from them, it can be seen through eyes of both normalcy and compassion.

In Patterson et al.'s (2014) need-domain of *support from my friends and other young people*, well-siblings expressed a need for support from their peer group and other young people whose siblings were affected by cancer. Developmentally this is a natural adolescent need because adolescents search out ways to understand the world around them by considering their peers' opinions (Broderick & Blewitt, 2002, p. 315). Therefore, it is understandable and healthy for well-siblings to look to both peers who are insiders of the cancer experience and also to their current friends to make sense of their experience. In their 2014 iteration of the SCNI, Patterson's group's recognition of well-siblings' needs regarding their current friendship circles

are illustrated in the following items: “my friends to understand what I am going through”; “to know how to talk to my friends about my experience with my sibling’s cancer”; “my friends to feel comfortable talking to me about my experience with my sibling’s cancer”; and the need for “support from my friends” (p. 656). Also under this domain is their need to speak to others who are either presently in the cancer experience or had previous experience with it: “to talk to someone my own age who has been through a similar experience with cancer”; “to be linked in with a social support network with others who share a similar experience”; and “to feel supported by peers who have a similar experience with cancer” (p. 656).

O’Shea et al. (2012) noted that the nurses’ opinion regarding the importance of supporting and encouraging the continuity of well-siblings’ interests and activities did not mean to suggest there is no need for flexibility on the behalf of well-siblings; nurses just presented this as one way of retaining a sense of stability during a time of great instability. The fact that O’Shea’s group decided to label this as *wanting a normal routine* (my emphasis), is interesting. I say interesting because in their operationalization they did not include or speak to a need for families to maintain specific routines like family dinners or bedtime routines, which may be impossible yet also important in fostering stability during times of crisis. Patterson et al. (2014), on the other hand, attended to these types of household routines in their domain *practical assistance*. In the SCNI, practical assistance needs are items such as: need for “assistance with managing daily tasks”; “for someone to take me to social events and activities”; “ assistance with jobs and chores around the house”; and “to have people around me who can help out by taking over some of the things my parent/s don’t have time to do anymore” (p. 656). Also under this domain is the need for connection to support services and being given information about support services.

Maintaining routines and remaining connected to personal activities and interests help bring a sense of normalcy to life beyond cancer for well-siblings (Murray, 1998). Stability allows well-siblings to maintain their own identity beyond being seen only as the sibling of a child living with cancer and asking, “Where do I fit in?” (DiGallo, 2003), or, “What about me?” (Murray, 1998; Prchal & Landolt, 2012). The well-sibling’s need to know they are still valid and important within their family (Patterson et al., 2014), and that their identity is more than just the sibling of the child with cancer, ties into the sub-theme of loss as reported by Wilkins and Woodgate (2005) and later by Woodgate (2006). Well-siblings’ identities often became defined in regards to their sick-siblings’ illness; Woodgate (2006) defined this as *loss of self within the family*, and included this as a component of loss within their first theme, *changing lives*. Siblings in Woodgate’s study reported feeling like the cancer experience belonged to their sick-sibling and their parents, not them. This is a matter addressed by Patterson et al. (2014) in their item: the need “for my family to acknowledge this is happening to me too” (under the need domain *understanding from my family*) (p. 657). In Woodgate’s study, well-siblings believed that they were not a part of the experience. This might be why well-siblings spoke about the illness not from their own perspective using “I” language, but from the voice of their parents and sick-sibling. For example this could look like the well-sibling responding to the question of “How are things going?” with a report of how the sick-sibling or parents were, while excluding their own thoughts and feelings on the subject. I witnessed this concept of not owning their own experience in the cancer diagnosis when I asked a 9-year-old brother of a sick-sibling I knew, what he thought cancer was and if it was impacting his life. To this he replied, “No, I don’t have anything to say. My brother has cancer, not me. I’m *just* a sibling.”

If a well-sibling's interests are encouraged and supported, and if their individual experience is acknowledged such that they feel seen and important, perhaps well-siblings would feel a clearer sense of identity within and outside of the cancer journey. As poignantly expressed by Sarah in the *Camp Goodtimes* sharing circle I facilitated, "I just wish they would ask me how I am!"

(d). Need for Support in Understanding and Expressing Intense Emotions. Not only do well-siblings tend to dismiss or diminish their own experience by not taking ownership of their "place" within the cancer experience, but well-siblings also report experiencing intense and confusing feelings. In their SCNI, Patterson et al. (2014) put a comprehensive focus on the need for emotional support through expression and validation of feelings. The domain is called *dealing with feelings*. There are 10 items under this domain that range from needing help to deal with feelings of anger, frustration, sadness, guilt, anxiety, and fear; to wanting to speak to family members and qualified professionals about these emotions.

Well-siblings have reported feeling deserted within the confusing and troublesome mix of feeling or thinking they are unworthy of expressing any suffering. For example, well-siblings in the Woodgate (2006) study essentially said that they believed they did not have the right to feel sorry for themselves because everyone else in the family had it worse than they did. Similarly my younger sister reported a belief she held about her own pain in comparison to my own, and a desire to not burden my parents:

Because cancer is such a big thing, and because I didn't want to burden anyone with what was going on with me, I started this belief that there was a value to pain and my pain wasn't as important as my sisters—because she had cancer. Even though I was dealing with anxiety, bullying at school, and feeling left out, all this was not relevant or of any

value because what my sister was going through was so much more important. I didn't want to be a burden to my parents because I could see that it was very stressful for them and that they are such strong people, but to see them shaken that bad, I guess I just realized that it was a really big thing. So I didn't want to add to their stress, and I tried to be quiet, and in the background, and fly under the radar. (J. Stonebridge, personal communication, October 21, 2013).

Related to this anecdote, in her study, Woodgate (2006) identified a theme called *committed to keeping the family together*. This theme reflected well-siblings' desire, perhaps even a sense of duty, to keep the peace in their families, making sure to not do anything that could increase stress levels in the family and cause further disruptions for the family. Not voicing their own concerns at the risk of causing more stress or pain for their sick-sibling and stressed parent(s) was one way siblings attempted to keep the family together.

In the Woodgate (2006) study, well-siblings tended to speak of guilt and how they should have been the one to get cancer. This is illustrated by the expression of one 17 ½-year-old in Woodgate's study:

I feel in a way that I am not doing anything because she was the one going through it I think. Most days I still think it should be me. It should be me, it should be me. My sister should be a normal kid again. (p. 409)

This sentiment of feeling guilty is another that I can also support anecdotally from my own experience and family. My older sister, who was 21 when I was diagnosed, had been a daily smoker since the age of 15. She shared with me the immense guilt and shame that she felt that I got cancer and not her. She reported thinking "Why Genny? When I am the person who makes bad choices. I wish I could take her place—if anyone had known how good of a person she is

then they would know I deserve it, not her. I should be the one who is sick.” (A. Stonebridge, personal communication, April 5, 2012).

Feelings of guilt related and unrelated to survivor guilt are addressed by Patterson’s group (2014) in terms of the sibling wanting to be able to talk about what is going on in their life—regardless of how their sick-sibling is—without feeling guilty. Similarly there is also a need to be able to have fun and enjoy activities without feeling guilty. Both of these last two points seem to connect to the aforementioned need for support to engage in their own interests and activities, which illustrates how these needs of well-siblings are not exclusive from each other. Perhaps the first step is the encouragement to engage in the activities, and the next step is to assure the sibling that it is okay for them to have fun and to not always be thinking of their sick-sibling. This type of reassurance may help the sibling experience their primary emotion of happiness and to mitigate their secondary emotion of guilt, which judges it as wrong to feel happy when their sibling is in pain.

(e). The Need for Honest and Open Family Communication. Through my review of the literature and readings of various case studies, it appeared to me that well-siblings reliably expressed the need for open and honest communication within their families. O’Shea et al. (2012) described siblings’ need for *wanting to know* and this is consistent with Wilkins and Woodgate’s (2005) finding that siblings desired truthful information regarding their sibling’s illness and specifically, that they wanted this information from their parents.

Buchbinder et al. (2011) described worries, questions, and doubts as challenges faced by well-siblings, and said that these challenges were best handled when there is open communication between family members. As I mentioned in the above section, while these needs are presented as exclusive of each other they are also dependent upon the other in order to

succeed. For example, as Buchbinder's group attested, in order for a well-sibling to express emotions there needs to be some form of open communication in their family. Wilkins and Woodgate (2005) described honest and open communication amongst family members as the act of being able to discuss feelings and fears about the cancer. This goes beyond solely communicating medical facts about the cancer diagnosis and treatment as with information giving and involvement of the well-sibling in the treatment of the sick-sibling. It asks parents and children to communicate with one another about their thoughts and feelings about the diagnosis and other life events during this time (Wilkins & Woodgate, 2005). Examples of items on the SCNI under the domain of *dealing with feelings* that speak to the need for communication within the family are: "to be able to express how I feel about my sibling's cancer without worrying about upsetting people"; "to know how to talk to my family about how I am feeling"; and "help with feelings about the possibility that my sibling with cancer might die" (Patterson et al., 2014, p. 657).

In a retrospective narrative study, DiGallo (2003) asked now-adult well-siblings and sick-siblings who had lived through childhood cancer to reflect from their adult perspectives about their experiences. Data gathered from this study illustrated how closely related the importance of open and honest communication and the need for information are. In one interview pair, both the well and diagnosed sibling reported how cancer had been a taboo subject within their family. Their mother referred to the sibling who was diagnosed with leukemia as "ill" during her 5 years of treatment. No-one in the family ever spoke about her having cancer and, as reported by both siblings, it would appear as though no one actually knew she had cancer. Even the diagnosed sibling who had cancer reported not knowing at the time she had leukemia. It was 8 years after initial diagnosis and after treatment was completed that their mother informed the siblings that it

had been cancer. The well-sibling reported feelings of confusion and guilt as she reflected back on how she behaved not knowing her sibling had cancer, and judged herself as having been selfish. This is an example of how lack of information and communication deeply impacted the experience of both the well and the sick-sibling over the longer term.

As I wrote above, Wilkins and Woodgate (2005) described open and honest communication amongst family members as the act of being able to discuss feelings and fears about the cancer. I also noted earlier how this definition of open and honest communication goes further than (just) communicating information and medical facts about the cancer. The implication is that the need for information is subsumed within siblings' overall need for open and honest communication. I suggest, however, the need for information exists at a lower and more pressing level and is connected more closely to the need for inclusion in the family experience of cancer, which serves to reaffirm and reassure the basic need for belonging. By being given information about their sibling's cancer they are more able to be included in helping their sibling—that they have a part to play, that they are involved and therefore, that they continue to belong despite the changes to dynamics and structure of their family and daily life. The need to discuss and communicate feelings and fears about their sibling's cancer emerges as a higher, although certainly not less important, need. Again this becomes another example of the ways in which these needs are interrelated and symbiotic with each other.

One nurse participant in the O'Shea group's (2012) study reported that some families chose to withhold information from well-siblings in an attempt to "protect" them from the information, fearing it would scare siblings. O'Shea et al. suggested withholding information could lead well-siblings to misconceptions and fears far worse than the actual reality of the illness. As the 14-year-old well-sibling in Murray's (1998) study recalled, "I felt helpless

because I did not fully understand what was going on. I knew so little about leukemia. I thought everyone who had it died. So I began to collect information, books and pamphlets” (p. 223).

O’Shea et al. were also of the opinion that withholding information contributes to behavioural problems. Patterson et al. (2014) have two other domains that support the need for family communication which are: the need for *information about my sibling’s cancer* and the need for *understanding from my family*. Items on the SCNI that support the need for the well-sibling to be communicated with and given information include: “to be spoken to by health care professionals in a way that I can understand”; “to be informed about my sibling’s condition—good or bad”; “information about the side effects of my sibling’s treatment” (Patterson et al., 2014, p. 656).

Regarding information giving, Malone and Price (2012) also supported the importance of this. They suggested that information facilitates understanding and reduces anxiety in siblings. Wilkins and Woodgate (2005) believed that the well-sibling who is given information is more able to master change, and incorporate it into their new view of their changing family structure. The physical impact of cancer treatment on a child is ruthless, including for example: hair falling out due to chemotherapy drugs; weight gain/loss due to medication and nausea; or physical deformation due to surgery (Canadian Cancer Society, 2011). Information helps well-siblings to understand and to psychologically prepare for the changes that will happen in their brother or sister. The physical deterioration of their sibling will be difficult for most siblings to witness, and more traumatizing without warning and information. Even the Canadian Cancer society speaks to the importance of information giving: “It’s common for both the parents and their child to feel that life has spun out of control. This can happen when you don’t feel you have all the information you need to make decisions” (2011). With all of these points in mind it is curious to consider why parents may choose to withhold information (in the context of open and honest

family communication) from well-siblings. Perhaps it is because parents themselves are looking for support, guidance, and permission. Perhaps it is because they lack the words and language; they too need support from helping professionals and research to guide them through the process.

Indeed, in the O'Shea et al. (2012) study, nurses said that they provided well-siblings with information depending upon age and maturity level *after* consultation with parents. Nurses reported often trying to have the parents explain the sick-siblings' cancer to the siblings, but reported that some parents felt discomfort with the task. The age of well-siblings at the time of their brother's or sister's diagnosis is thought to impact how they cope with information and how they are affected (McGoldrick et al., 2005 p.156; Vermaes et al., 2010). One paediatric oncology nurse in the O'Shea et al. study stated the following: "I think the teenagers are much more into what the medical therapy is, whereas the younger kids, school age or preschool age, they are more into playing with syringes or medicine cups. It's play versus knowledge-based information" (p. 225).

To further this discussion about communication with younger versus older siblings, I present information from a meta-analysis of the effect on siblings who have a brother or sister with a chronic health condition (CHC)³ by Vermaes et al. (2010). In their study they suggested that younger siblings may be protected from higher anxiety levels regarding their sibling's illness, because of their lack of knowing, or, what the authors described, as their "naivety" (p. 172) regarding the CHC. Further, they go on to report how they believed younger siblings are less vulnerable than older siblings because older siblings not only have the cognitive ability to understand the consequences of the CHC, but also because their age often requires them to be more self-sufficient in the family's new dynamic. However, a limitation of the Vermaes et al.

³ In the analysis of chronic health conditions, childhood cancer cases represented 11 out of the 56 CHC cases that were reported on.

study is that “older” and “younger” siblings were defined in terms of birth order: siblings were either older or younger than the sick-sibling. In other words, Vermaes et al. failed to operationalize what ages they quantified to be “younger” and “older” aged siblings. This means, therefore, that both a 6-year-old well-sibling of a 12-year-old sick-sibling and a 14-year-old adolescent well-sibling of a 16-year-old sick-sibling, would be considered “younger” siblings; and a 7-year-old sibling of a 2-year-old sick-sibling and a 14-year-old sibling of an 11-year-old sibling, would be “older” siblings. A birth order operationalization of “younger” and “older” siblings is therefore very different in meaning to—and will provide different information from—an age-range operationalization (e.g., younger siblings = 12 years and younger; older siblings = 13 years and older). Vermaes et al. furthered this questioning when they said they believed there may have been “reporter-effect” in the studies, as often younger siblings’ experiences would be reported by their parents, while older siblings self-report.

Adams and Deveau (1987) discussed the vulnerability of the adolescent sibling when faced with a sibling who is dying from cancer. It is important to acknowledge that whether or not a cancer diagnosis is terminal, the diagnosis is almost always life-threatening, meaning the possibility of death lingers. This is a fear that Patterson et al. (2014) captured in the item on the SCNI, which states the need for “help with feelings about the possibility that my sibling with cancer might die” (p. 657). Adams and Deveau (1987) contended that it is adult-like treatment of adolescent siblings that is most detrimental for them. Adolescent siblings can be expected to “handle” it better than a younger sibling who is assumed to require (and therefore often given) more support and guidance. This differential treatment often results in adolescent siblings believing they have to manage their thoughts, fears, and emotions on their own. Therefore, it seems reasonable to assume when, for example, information about the facts of the cancer

diagnosis are presented to the well-sibling, their ensuing emotional reactions will require attention-giving. This attention-giving and validation of the emotional experience will be most appropriately given through honest and open communication from caregivers, family members, and medical professionals (DiGallo, 2003).

Personally I can attest to this need for information. When I was going through chemotherapy and radiation my little sister was never informed about the potent effect or purpose of my treatments. In talking with her recently, she told me how, in the months during treatment, she begrudged and did not believe my “lazy” behaviour of lying around on the couch after the impact of chemotherapy treatments left me nauseated and exhausted. She shared how she thought the chemotherapy was what was going to make me better from cancer, and therefore thought it should not make me so violently ill. Regarding the need for information, my sister told me the following:

I think more an explanation of what [you were] going to be going through and what it was going to look like would have been helpful to me. I think there was one memory of, I made toast, and and the smell of it made [you] nauseous and...ill and made [you] puke, and that little thing that I did, I thought it was my fault, and that I couldn't do anything without it creating some sort of problem. So if I had some explanation that [you were] going to be so sensitive to smells, that it was going to make [you] sick because of the chemo and how it affected [your] body, so that I didn't take on that responsibility that it was my fault.

She reported feeling frustrated and confused when I was sick, and later guilty for feeling this way. She internalized these feelings as a 13-year-old, yet now as a 26-year-old she is able to articulate how she did not understand the purpose of and impact chemotherapy would have on

my body and me. She was left in a mystery to fill in the blanks about what she thought I was experiencing. Without information, my sister experienced a range of emotions from anxiety, confusion, sadness, anger, and guilt (J. Stonebridge, personal communication, February 7, 2013).

In summary, through my reading of the literature I synthesized five overarching needs of well-siblings: (a) the need for attention; (b) the need for involvement in the care of the sick-sibling; (c) the need for support, routine and continuity in personal interests and activities; (d) the need for support in understanding and expressing intense emotions; and (e) the need for family communication. These are needs that too often go unmet, due to a time of crisis that makes it difficult for family members and professionals alike to look beyond the sick child (O'Shea et al., 2012). The studies outlined in this review provided a rich foundation from which I developed my research question and envisioned my research methodology.

Research Objectives, Rationale and Question

Objectives

Two primary objectives guided my research study. One was to supplement the research that has been done on the experience and needs of siblings of children diagnosed with cancer, a population that is largely overlooked during the cancer experience (Alderfer et al., 2010; Patterson et al., 2011). The second was to identify and extend existing knowledge on the needs of adolescent well-siblings, specifically. Identification of these needs will further the conversation of how we might best go about actively supporting adolescent well-siblings during the course of the cancer experience, which is *their* cancer experience too. While different from that of their sick-sibling or their parents, inasmuch as cancer affects all family members, the cancer experience also belongs to the well-sibling. By looking retrospectively at the age category of adolescence and to what their needs were and how effectively these were or were not met, I

aimed to gather the wisdom of now-adult participants in the hopes of helping future adolescent-aged siblings who have a brother or sister diagnosed with cancer.

Rationale

Cancer is a disturbingly common word in North American society, and yet regardless of its familiarity, it always instils a reaction of shock, fear, and heartbreak. The psychosocial impact cancer has on the diagnosed child is life changing and all members of the family will experience varying degrees of disruption and distress (Patterson et al., 2014). For the past 50 years, cancer's psychological, physical, and emotional impacts on a child diagnosed with cancer and their parents are vantages that have been explored extensively (Wilkins & Woodgate, 2005). However, there is a group of somewhat silent observers that need to be heard: the brothers and sisters of the child who is diagnosed are also deeply impacted by the cancer diagnosis and treatment. It can be roughly estimated that in 2011 approximately 1,200 well-siblings had a brother or sister diagnosed with cancer, and there were another 8,000 siblings already living with the experience of being a sibling of a child with cancer in Canada (Statistics Canada, 2013). Understanding the impact on and experience of siblings is still in its infancy, and deserves and requires more research attention and focus (Alderfer et al., 2010; Buchbinder et al., 2011; Patterson et al., 2011; Wilkins & Woodgate, 2005). Awareness is building, however: Alderfer et al. (2010) reported that between 1999 and 2009 there were more studies published on siblings of children with cancer than in the previous 40 years combined. Despite this momentum, the needs of well-siblings continue to be neglected (Ballard, 2004; Murray, 1998; O'Shea et al., 2012; Wilkins & Woodgate, 2005; Woodgate, 2006), under-researched, and underserved (Patterson et al., 2011). What is clear from the limited research is that the needs of an adolescent are affected when a sibling is diagnosed with and treated for cancer.

Furthermore, previous research has indicated that well-siblings are at risk for psychosocial issues (Barrera et al., 2004; Malone & Price, 2012; Woodgate, 2006), and these issues often develop as a result of some of their essential needs being unmet during their sibling's cancer treatment (Alderfer et al., 2010; Malone & Price 2012; O'Shea et al.2012). Identifying and describing the needs of adolescent siblings is therefore an important step in addressing this gap in the lived experience of well-siblings by raising awareness and bringing information to parents, caregivers, and professionals supporting and working with the child with cancer.

Research Question

Given the research objective and rationale for this study, my research question is: What are the needs of adolescents who have a sibling who is diagnosed with and treated for cancer? I sought to answer this question by collecting retrospective narrative interview data from now-adult siblings who had been of adolescent-age (11-18 years) when their sibling was diagnosed with, and who lived through, cancer.

Chapter Summary

In this chapter, I have presented an introduction to the topic, my researcher location, along with a background in needs theory. I reviewed a selection of previous literature that pertains to experiences of well-siblings who have a brother or sister diagnosed with cancer. A thorough review of the ways in which research has already looked at the needs of well-siblings was also presented (O'Shea et al., 2012; Patterson et al., 2011; Patterson et al., 2014; Wilkins & Woodgate, 2005). Previous research indicates that well-siblings are at risk for psychosocial issues such as loneliness, depression, etc. (Barrera et al., 2004; Malone & Price, 2012; Woodgate, 2006), and that these issues often develop as a result of some of their essential needs

being unmet during their sick-sibling's cancer treatment (Alderfer et al., 2010; Malone & Price 2012; O'Shea et al. 2012). However, there are still gaps in the literature and well-siblings' needs continue to go unmet (Alderfer et al., 2010; Wilkins & Woodgate, 2005). A critical element that previous research has not specifically attended to is to focus on the needs of specific age categories. My study attends to this gap in the literature. I focus on the needs of adolescent siblings, as seen through the retrospective voices of now adult well-siblings, who were adolescents when their siblings had cancer. In the following chapter, I will discuss the qualitative research methodology that informed the design of my study.

Chapter 2

Methodology & Method

In this chapter I will describe qualitative research and why this methodology aligns with both my research question and me. Next I will explore the philosophical location from which my research has developed, and then describe the phenomenological design of my study and narrative interviewing as the method I selected for data collection. Following this I will describe my participants and recruitment methods. I will next describe the process of data collection, and of thematic analysis as my method of data analysis. I will end by explaining how I ensured and assessed the trustworthiness of my data and findings.

Methodology

Qualitative Research

Qualitative research offers a mode of inquiry that seeks to understand a particular human experience or phenomenon through exploring the views and experiences of participants (Creswell, 2009, p. 4). The qualitative researcher does not seek information in order to generalize and reduce a phenomenon to something that can be measured, as in quantitative research (Creswell, p.16). Rather, he or she seeks for a holistic, rich, and descriptive understanding of the human experience within particular contexts (Haverkamp & Young, 2007; Walker, Cooke & McAllister, 2008). Haverkamp and Young (2007) asserted that the core purpose of qualitative research is to understand, compared with explanation as the core purpose of quantitative research.

Qualitative methods stand in contrast to quantitative methods, which aim to build and test theories through the process of hypothesis testing by the collection of observable and therefore, measurable or quantifiable data. Findings from these quantitative data will then either support or

refute a preconceived hypothesis with the hopes of being able to make generalizations (Creswell, 2009, p. 4). The quantitative researcher adopts an objective and arms-length approach to the collection, analysis, and interpretation of data, and employs and describes measures taken to ensure the validity and reliability of the study. However, unlike the qualitative researcher, the quantitative researcher does not involve or see their person as a co-creator of the data collected. They do not engage in the same level of reflexivity and detailed accounting for the possible effects of their role and implications thereof for the findings of the study. In contrast, the qualitative researcher is asked to consider in great and reflexive detail how they factor into the research process, and to remain reflexive and aware of how they themselves will possibly shape their interpretations of the study (Creswell, 2009, p. 177). Qualitative methodology requires researchers to immerse themselves in rich and experientially detailed accounts of a phenomenon; from this, an understanding of their chosen phenomenon is developed, rather than used to validate preconceived ideas (Marshall & Rossman, 2011). The participant is seen as the expert of their experience, and the researcher as seeking to “learn from the meaning the participants’ hold about the problem or issue, not the meaning that the researchers bring to the research or writers express in the literature” (Creswell, 2009, p. 175).

In discussion of what qualitative methodology is or is not, I think it necessary to point out what Krefling (1991) noted: that often qualitative research is defined by comparing it to quantitative research and its methods. In so keeping, my understanding of qualitative methods has indeed developed through this comparison. Perhaps this is also a function of natural happenstance given the history of qualitative methods within the historical development of psychology. As Morrow (2007) explained, in the late nineteenth hundreds and early twentieth century, psychology sought to prove itself as a hard science. Methods such as data diaries,

detailed observations, case studies, and interviews lost credibility, while experimental methods and statistical analysis became more “legitimate” forms of measurement (Morrow, 2007).

However, in the past 30 years qualitative inquiry has evolved to become a respected form of inquiry, notably because of the way it addresses the power imbalance of researcher as expert, and instead asks researchers to reflexively consider “whose reality am I portraying?” (Morrow, 2007, p. 223). Further to this, Morrow (2007) reflected on the paradigmatic shift qualitative methodology made from a positivist to post-modern worldview, challenging how we pursue knowledge.

While I do align myself with qualitative methodology as a researcher, I also respect quantitative research as a valid and helpful form of inquiry that offers a vantage point that qualitative research cannot and vice versa. Creswell (2009) points to the importance of seeing quantitative and qualitative approaches as different perspectives that exist on a continuum—rather than as dichotomous (p. 3). He asserts they each have differing philosophical assumptions, research strategies, and research methods. You will have seen for example in my literature review, that much of the previous research on well-siblings’ experience is a combination of both qualitative and quantitative analysis. Both contribute unique and different ways of knowing and understanding. Therefore, rather than saying one is better than the other, I instead respect that each approach has their own strengths and are able to answer different kinds of questions.

The purpose of my research was to gain understanding and wisdom from the voices of adults who had been an adolescent when their sibling was diagnosed with cancer. As such, my research was an exploratory attempt to describe the subjective lived-experience of well adolescent siblings of brothers and sisters diagnosed with cancer. Specifically, I wanted to identify needs of well-siblings, thus my research question: “What are the needs of adolescents

who have a sibling who is diagnosed with and treated for cancer?” I consider well-siblings as the experts of their experience, and believe that retrospective/adult hindsight perspective can offer valuable knowledge. DiGallo (2003) spoke of the importance of gathering the subjective experience of siblings as opposed to asking oncologists or parents what the siblings’ experience is. In regards to the importance of gathering the *subjective* experience most specifically of siblings, DiGallo (2003) write: “purely evaluation is [thus] not possible, since life is a *quality* and always contains an ‘excess’ that cannot be measured quantitatively” (p. 499).

Furthermore, the systematic review by Alderfer et al. (2010) of both quantitative and qualitative research supported the idea that qualitative research appears to capture a picture of the sibling experience in a way that quantitative research is not able to. Through their review of qualitative sibling studies, Alderfer’s group found that siblings experience appreciable and sizeable psychological discomfort (e.g., depression, anxiety, and difficult emotions such as frustration and guilt) in the months following the cancer diagnosis. In contrast, many quantitative studies report no significant reports of emotional or psychological distress in siblings when contrasted with comparison groups (Alderfer et al., 2010). Alderfer’s group suggested this could be due to qualitative research methodology facilitating researchers’ ability to gather rich information and therefore to inform the questions that quantitative studies are asking. This was evidenced in the way Patterson et al. (2011) went about creating their *Siblings of Cancer Needs Inventory* (SCNI): they began by using qualitative interviews and then extrapolating this information to a quantitative questionnaire.

According to Morrow (2007), the relationship between the qualitative researcher and participant is an intimate one in which the participant often shares information of an “emotional and sensitive nature” (p. 217). Hopefully with the establishment of trust the participant will feel

comfortable enough to share their stories honestly and openly with the qualitative researcher (Morrow, 2007; Striano, 2012). Morrow (2007) also speaks to how the congruency of qualitative methods aligns with a counselling psychologist's values and practice. As a graduate student in counselling psychology I agree with her sentiment in several ways, such as seeing my clients as being the experts of their own experience, and working in a collaborative way to co-create sessions and desired goals for counselling. Similarly, in my research I worked in a collaborative conversational manner with participants, honouring their inherent wisdom and the knowledge of their stories. It was my intention to establish a safe, trustworthy rapport with my participants in the same way I work with my counselling clients. It was important for me to be congruent (i.e., genuine, integrated, authentic, and fully present in the relationship [Corey, 2009, p. 174]) while at the same time retaining professional boundaries in the research relationship, the same as I would in a counselling session. I think that congruency is a quality essential in the counselling relationship in order to build safety and rapport. Thus, the opportunity to “do” research in a way that is congruent with the values with which I live and practice counselling by was exciting and important to me and another reason why qualitative research is a good fit for me.

As I noted earlier, the qualitative researcher is expected to be self-reflexive and aware of the philosophical underpinnings that guide their research questions (Haverkamp & Young, 2007). Whereas reflection is the process of witnessing one's own experience and exploring the self through active introspection (Amulya, 2006), reflexivity involves the researcher not only being self-introspective, but also considering self in relation to the research by inspecting her “conceptual baggage” (Kirby & McKenna, 1989, p. 32). Conceptual baggage is the term Kirby and McKenna (1989) use to describe the researcher's thoughts, ideas, life experiences, biases, and values which interact with the data and shape the analyses and sense-making of data.

However, reflexivity is not always practiced. I remind my reader of the work of Wilkins and Woodgate (2005) who reviewed solely qualitative articles on the experiences of siblings of children diagnosed with cancer, identifying 27 studies that looked at well-siblings' perspectives. In their critique of previous qualitative research, Wilkins and Woodgate commented that researchers had a tendency to omit the philosophical approach that guided the study or upon which the study was based. This is a reproach echoed by Alderfer et al. (2010) who argued that too often in published qualitative research, researchers do not identify their philosophical underpinnings and biases as is appropriate for qualitative research.

Further to variable levels of reported reflexivity, Wilkins and Woodgate (2005) also recognized a lack of specificity in the qualitative research designs examined for their study. Fourteen of the 27 studies employed in their review were called *descriptive, exploratory designs*. Wilkins and Woodgate reported that these 14 studies gave valuable information but lacked the comprehensive understanding that can be gained from more specific research designs such as *lived experiences* or *narratives* (italics not in the original). Further criticisms from Wilkins and Woodgate (2005) pointed to researchers who chose qualitative research designs based upon convenience rather than philosophical and methodological coherence with the research question being asked. To this end I will next attend to these criticisms by talking about my own philosophical location and how this influenced my study design and selection of methods for data collection and analysis.

Philosophical location. Haverkamp and Young (2007) stated there are important considerations a researcher must take when formulating a research question and choosing an appropriate research design to answer their research question. Therefore, before I share how I collected and analyzed my data I will discuss how I attended to these considerations. These

considerations are: (a) what is the purpose of the intended research; (b) what is the philosophical/theoretical stance of the researcher; (c) what is the interpretive/explanatory/hermeneutic approach of the researcher; and (d) how do these three points align with the research question and goals? I have clearly stated the intended purpose of my research under my statement of objectives at the end of my literature review: to supplement the research that has already been done on this under-researched population, and to identify and extend existing knowledge on the needs of adolescent well-siblings.

In keeping with Haverkamp and Young's second question, Creswell et al. (2007) also urged the researcher to first locate themselves in the research process by considering their philosophical assumptions about ontology (assumptions made about the reality or nature of the world, and the nature of being), epistemology (theory and nature of knowledge and how we know these assumptions about reality to be true), axiology (what is important, one's values), and their chosen methodology. Speaking generally about qualitative research Walker, Cooke, and McAllister (2008) said the following:

There are no rules or formulas to determine how much data to collect, who to collect it from, and what kind of data should be collected, nor are there any computer packages or mathematical formulas to tell researchers what their data mean. Researchers must make these decisions based on their experience, knowledge, and strategy of inquiry from within the philosophical and theoretical framework they have chosen. In presenting the results of their study, they must also demonstrate the veracity and relevance of their interpretations and of the meaning of their work. (p. 83)

It was essential for me to carefully consider these important recommendations and guidelines for creating a solid philosophical/theoretical foundation upon which to do my qualitative research. I

discussed and explored the complex terms of ontology and epistemology with my supervisor, in research methodology courses, and with fellow qualitative researchers to come to an understanding of my positioning and how it applied to my research on the well-siblings of children diagnosed with cancer.

In order to discuss these constructs I must first orient myself to the theoretical position/paradigm through which I regard these concepts, which will describe the role that philosophies play in the research process (Mayan, 2009, p. 25). Morrow (2007), described the paradigm as the “net” containing the researcher’s ontological, epistemological, axiological, and methodological assumptions (p. 212). The “net” or paradigm I align with is postmodernism—the questioning of ‘truth’ and ‘reality’ and the sources of ‘knowledge’ (Grbich, 2012, p. 5). My ontological stance is relativism. Ontology asks: “What is the nature of reality? What can be known?” (Guba & Lincoln, 1994 cited in Mayan, 2009, p. 24) “What can be apprehended” (Mayan, 2009, p. 24), or found or uncovered? As a relativist constructivist, I believe that multiple socially constructed realities exist at any one time and that each one is equally valid (Haverkamp & Young, 2007). I agree with Morrow (2007) who said: “there are as many realities as there are participants (plus one: the investigator)” (p. 213). I believe this is in keeping with my position stated earlier where I wrote how my intent for this study was to consider well-siblings as the experts of their experience. This reflects the place from which I operate; notably from a place of valuing the subjective truths of my participants and the intersubjectivity that would occur between us.

Epistemologically, I believe that knowledge is socially co-constructed in and through our interactions with others, and that each person involved in an interaction will have their own story about how they see the world and their experience of reality; this is social constructivism. Social

constructivism, which sees reality created by the language and actions human beings use to engage with the social environment and the social environment's reciprocal influence on the individual or the mind. In other words, the reciprocal processes between the individual's mental processes (or the mind) and the social environment shape the development of the individual and of his or her sense of reality (Moen, 2006). As such, a qualitative social-constructivist researcher sees the production of knowledge as a dialogical, intersubjective, process between researcher and participant (Morrow, 2007). I believe that through diverse and multiple social interactions each person creates a story of how they see the world and experience reality—and, through these lived experiences their knowledge is iteratively co-created and revised. Therefore, because I believe knowledge-through-experience is a powerful way of knowing, I also believe, like Moen (2006), that knowledge is relative and subjective.

My axiology (that which I value) is woven into every step, thought and word in this research. For example, I place value in the subjective experience of the well-sibling and value authentic connection and congruency; I have conducted my research such that I have been able to be congruent in the connections I have fostered. I have also been true to my value of allowing my participants, as the experts in their lived-experience, to lead during our times of connection. In a cancer diagnosis I value and believe each story of each family member. Each member will be impacted by and “know” the diagnosis differently. Members will derive their own subjective understandings, meanings, and truths about the cancer diagnosis through their interactions, or lack thereof, with others. It is my belief that all views are valid. I value equality, and think it is important to allow each family member the space to have his or her voice heard. In my counselling work with clients I respect and hold a family systems perspective in the work I do with both adults and children. By this I mean that I hold the consideration that past and present

family dynamics, experiences, rules, and relationships impact the client's self-concept and ways of knowing the world (Corey, 2009). While I respect and use the systems approach, I also believe in the importance of attending to each individual within the family and understanding their unique story. To this end, it was important for me to focus solely on the story of the well-sibling. This also aligned with the recommendations of researchers (e.g., Wilkins & Woodgate, 2005), who noted a gap in the literature: previous research has focused largely on the experience of the sick child and the parents.

I also believe that within the context of research, meaning is co-created between researcher and participant. As a consequence, I believe that my own cancer experience absolutely influenced both how and why I approached the research, and I value this. This personal connection thus required me to remain reflexive. Through my own, and my participants' collaboration of viewpoints, my guiding social constructivist comprehension was that a deeper level of understanding would be created. Taken together, I consider myself to be a relativist ontologically, and a subjectivist epistemologically, working within a social constructivist lens.

Constructivism/Social Constructivism. Constructivists assert that an individual makes sense of the world around them through cognitive processes and literally "construct" their experience to integrate knowledge and create meaning (Young & Collin, 2004). Under the umbrella of constructivism are several different positions, one of which is social constructivism, which "recognizes that influences on individual construction are derived from and preceded by social relationships" (Young & Collin, 2004, p. 376). Reality is seen as being mutually influenced by society, politics, culture, history (Walker, Cooke & McAllister, 2008), and the individual mind (Moen, 2006). According to Gergen and Gergen (2008) the essence of social

construction is that “everything we consider real is socially constructed. Or, more dramatically, *Nothing* is real unless people agree it is” (p.10) It is important to distinguish social constructivism from social constructionism. What distinguishes social constructionism is that knowledge is created and suspended in social interaction. In social constructivism, knowledge about reality is reflectively created (but sometimes uncritically assimilated) in the individual mind through cognitive processes (Young & Collin, 2004) and structures (e.g., schema), in response to social interaction (p.11) and social transmission of ‘knowledge’ and ‘truth.’

As a researcher aligned with postmodernism, I believe therefore that the knowledge data I collected is relative and subjective. As reviewed by Haverkamp and Young (2007), the data were constructed through participant-researcher collaboration—in this case, the collaboration was between my participants and me. I further believe the knowledge that we created was influenced by social process (e.g., the more formal conversational environment given the research context) and by each of our individual cognitive constructions of meaning. The constructivist researcher believes their values, personal beliefs, and character will not only influence the research (Morrow, 2007; Walker et al., 2008), but also make the research meaningful (Haverkamp & Young, 2007; Koch, 1994). Indeed Marshall and Rossman (2011) make the compelling argument that it is a necessity for the qualitative researcher to do research that is meaningful to them. They state that the researcher who cares deeply about their research reinforces the “want-to-do-ability” of the study, which will sustain the researcher in the long run of the research process.

As a constructivist qualitative researcher I believed in beginning from the place of my direct experience as a source of knowing, and then turning to the experts (Haverkamp & Young, 2007)—in this case, to the well-siblings of children diagnosed with cancer. I first reviewed the literature on the sibling experience of cancer diagnosis and treatment, and then turned to my

participants to help me further understand the sibling lived experience by focusing most specifically on what their needs as siblings were. In order to gain a deeper understanding, I am adamant in thinking we must hear the stories from the individually-minded realities of siblings.

Method

Maybe stories are just data with soul- Brené Brown

The type of research question asked will determine the method and design of the study (Creswell, Hanson, Clark Plano, & Morales, 2007). The five most widely used and known qualitative methods are: narrative inquiry, phenomenology, grounded theory, case study, and participatory action research (Creswell et al., 2007). A question that asks for a chronological story-orientated account of an experience would best be asked from a narrative inquiry approach, whereas a question that sought to describe and understand the specific essence of an experience would be best answered by using a phenomenological approach (Creswell et al., 2007). The intent of grounded theory is to generate theory, and is concerned with basic social process questions, and how things change through stages and phases. Case studies look for an in-depth understanding of a particular case, and participatory action research looks to working with members of a community in order to facilitate change within communities (Creswell et al., 2007). Because the purpose of my research was to gain a retrospectively-informed understanding of the experience of adolescent siblings of children diagnosed with cancer as told from the perspective of (now adult) siblings themselves, a phenomenological approach is well-suited. I wanted to understand their lived experiences in their own words, from during diagnosis and through treatment. Most specifically, by inviting and listening to siblings' stories of their experience, I hoped to gain a greater understanding of the essence of the adolescent well-sibling experience in terms of the needs of the siblings during the cancer experience. The purpose of

phenomenological research is to describe the universal essence of a specific phenomenon (e.g., the needs of being an adolescent well-sibling with a sibling with cancer) (Creswell, 2007, p. 58). Moustakas (1994) describes that the phenomenological research question seeks to “reveal more fully the essence and meanings of the human experience” (p. 105). This is done by gathering the lived experiences of several individuals and seeking a distillation of what all the participants have in common, through an understanding of “what” they experienced and “how” it was experienced (Moustakas, 1994, p. 115). Phenomenology has strong philosophical roots drawing heavily on the writings of Husserl (1859-1958) and those who expanded on his views such as Heidegger, Sartre, and Merleau-Ponty (Creswell, 2007, p. 58). These philosophical underpinnings align closely with my own epistemological and ontological beliefs, as Moustakas (1994), who was summarizing Husserl (1970), wrote, “the objective is the manifest presence of what appears and can be recognized only subjectively by the person who is perceiving it” (p. 47).

Further to deciding on the appropriateness of using phenomenology as a qualitative approach fitting of my research question, Moustakas (1994) says that the phenomenological research question: “grows out of an intense interest in a particular problem or topic. The researcher’s excitement and curiosity inspire the search. Personal history brings the core of the problem into focus” (p. 105). Therefore, the phenomenological approach using a narrative positioning fits well with both my research question, philosophical orientation of social constructivism, and my personal history and “excitement” about the research topic.

Research Design

I designed my phenomenological study using a retrospective design to explore a convenience sample of now-adult participants’ stories of their experience of being the well-siblings of children and youth diagnosed with and treated for cancer. Most specifically, I was

interested in listening for, understanding, and identifying the needs of adolescent-aged well-siblings in families of children and youth receiving treatment for cancer. To listen to the stories of now-adult well-siblings, I adopted a narrative positioning.

Narrative Positioning. *Stories have to be told or they die, and when they die, we can't remember who we are or why we're here*" (Kidd, 2002, p. 107). Stories, or narratives, are how we make sense of the world around us and give meaning to our lives (Polkinghorne, 1988). A narrative positioning assumes that an individual "lives" the experience of a phenomenon by creating their own reality based upon how they interpret and narrate their life stories (Marshall & Rossman, 2011). In other words, an individual socially constructs their narrative through cognitive processes; narratives frame an individual's lived experience, which in turn creates their reality—their individual truths (Coulter & Smith, 2009 as summarized by Clandinin & Connelly, 2000). There are a number of realities, all of which are constructed by individuals through social interaction and discourses within the family, peer, social, cultural, historical, and political contexts. As Randall (2013) writes "the self and story are intricately entwined" (p. 175). Our stories become units by which to understand our human existence, our surrounding cultural and social world, and our lived (phenomenological) experiences. Di Gallo (2003) also suggested that the creation of inner narratives as well as the narratives we communicate with the outside world, give meaning and form to our experiences, which can allow for reflection and the ability to cope with and to accommodate difficult events (such as a sibling's diagnosis of cancer).

Retrospective points of views. As I reported in Chapter 1, Lehna (1998) suggested the need for retrospective studies to address the well-sibling's experience of cancer so as to gain valuable information from the grown siblings' articulate point of view. While adult retrospective memories may be impeded by a memory bias, retrospective findings may prove more beneficial

because adults possess greater self-knowledge than children and adolescents when reflecting on their experience (Pompeo, 2009). The argument that a retrospective study may be lacking in truth as a by-product of time and life-distance between the participant and the memory, could also be challenged from the constructivist point of view. Constructivism would argue that the experience of the event as remembered and versioned *now* is the truth and reality for that individual. In a retrospective study of adult childhood cancer survivors and their siblings, DiGallo (2003) agreed that memories are subjective to being altered by time, distance, and the experience of the storyteller. However, he argued that recounting a lived experience with time and distance, as in a retrospective study of a lived experience of illness, affords storytellers an opportunity to safely engage with experiences that may have been too threatening or explosive to talk about during the time of the illness. Murray (1998), like Di Gallo, also used a retrospective phenomenological case-study research design to gather wisdom from siblings; Di Gallo's participant was a well 14-year-old sibling who was 12-years-old when her sibling had cancer. Through this retrospective study important and meaningful knowledge was gained about the well-sibling's experience.

I believe there is also the consideration that hindsight retrospectives can carry wisdom. In a culture that tends to "put away" the elders of our population into nursing homes and to worship youth culture or ask Siri⁴ and Google for advice, it can be hard to remember the practice of honouring the wisdom of those who have made the journey and lived to tell the tale. I am extrapolating the wisdom of elders to the wisdom of the experience of now-adult well-siblings.

Randall (2013) defines wisdom as "a deepened knowledge of the stories of our lives" (p. 164).

Wisdom later in life is often through the recognition of the impermanence of life and mortality—

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1. **Siri** is an application for Apple Inc.'s iOS (iPhone Operating System), considered as a personal assistant and knowledge navigator it answers questions, make recommendations, and performs actions.

a reality which childhood cancer can catapult young people into experiencing long before what is normative. I remind the reader of the “wisdom” in Murray’s (1998) single-case qualitative study, where the 14-year-old well-sibling said: “I learned something valuable from watching life struggle against death. I learned that peace is everywhere, even in the time of deepest trouble...There is a good and bad to everything in life” (p. 223).

A further impetus for focusing on the retrospective wisdom of adult perspectives came from my own personal experience with my younger sister. I remind my reader that my younger sister, Jasmine, was 13 when I was diagnosed with cancer at the age of 18. It took us both into our adult years to find the awareness of, words for, and wisdom about how my cancer diagnosis impacted Jasmine and also shaped our sibling relationship. I did not consider the effect “my dance with cancer” had on Jasmine and our sibling relationship until I was 26-years-old and working for *Camp Goodtimes* (as I have spoken to previously in my literature review). This awareness came after I had processed my own experience through therapeutic modalities such as narrative and art therapy, and also after I had communicated with my parents about the experience and how they were deeply impacted by it. However, Jasmine recently reported to me that it was not until she was 22-years-old that she started to reflect on how she, as a 13-year-old, was affected by being my sister during the cancer experience. My little sister told me that, “I never really thought about how it impacted me...it was just *your* experience, and I remember feeling very angry at you but I wasn’t sure why, and I felt like a bad person for feeling angry at you” (J. Stonebridge, personal communication, July 3, 2013).

Overall, I acknowledge the possibilities of memory bias *and* greater self-knowledge, and of wisdom, hindsight, and perhaps insight through retrospection. It was, nonetheless, my strong belief that a retrospective study would provide sensitive, meaningful, and useful information

about the lived experience of well-siblings. Information that could help current well-siblings and their families, as well as medical and counselling professionals and helping service-workers (e.g., *Camp Goodtimes* volunteer leaders) working with paediatric cancer patients. Taken together, a phenomenological study using a retrospective design including a convenience sample of now-adult well-siblings, fit well with both my research question and philosophical orientation.

Participant Recruitment and Participants

Ethical approval for my study was obtained from the University of Victoria's Human Research Ethics Board (HREB). My inclusion criteria required that prospective participants were: (a) adults (aged 19 and older); (b) adolescents (ages 11-18 years) when their sibling was diagnosed with, treated for, and survived cancer (where survived was defined as being treatment free for at least 2 years and not living in a terminal or palliative phase of their illness); and (c) proficient in spoken and written English. (I provide further discussion of ethical consideration later in the subsection headed "Reflexivity" on page 89.)

Participants were recruited through posters placed around local coffee shops, as well as on the campuses of the University of Victoria. UVic's Educational Psychology and Leadership Studies sent out my recruitment poster on their list-serve to students and faculty members. Childhood Cancer Canada, an organization that awarded me a scholarship in support of my research in 2012, also put out a general posting to persons on their list serve. The Canadian Cancer Society helped me by recruiting participants through their list-serve and database of persons who had already submitted to be contacted for research purposes. Because I am an insider within the cancer community I have some connections with individuals whose lives have been affected by childhood cancer, for example through my experience working through *Camp*

Goodtimes. Friends and relatives also helped to recruit participants through posting my research poster on their Facebook pages and through word of mouth.

Posters and social media postings asked, “Did your sibling have cancer? Would you like to share your story? If you were an adolescent when your brother or sister was diagnosed with cancer I would like to hear your story.” Further exclusionary criteria were defined on the poster such as required current age of participants and current health status of cancer affected siblings. I clearly stated to friends who referred people to me to allow the participant to contact me directly so as to provide that person with confidentiality.

My study sample comprised 7 females all over the age of 19 ($M = 25$, range = 20-30 years, $SD = 4.2$). Well-siblings’ mean age at time of diagnosis was 12 years (range = 10-17 years, $SD = 2.7$) and the mean age at end of treatment was 13.9 years (range = 12-17, $SD = 1.94$). The mean time since their brother or sister’s diagnosis was 13 years (range = 10-19 years, $SD = 3.3$), and the mean time since the end of their sibling’s treatment was 11 years (range = 7-17 years, $SD = 3.9$). The mean age of the sick-sibling at time of diagnosis was 9.1 years (range = 3.5-17 years, $SD = 5.3$). Participants included two younger siblings, one of whom was a middle child, and five older siblings. (One of the older siblings was a middle child who had an older sister who suffered from another non-cancer related disease. This participant’s older sister died 5 years after her brother completed his cancer treatment.) Of the sick-siblings, 3 were younger brothers, 2 were younger sisters, and 2 were older sisters. Three participants had more than one sibling. All participants were proficient in reading and writing in English. One participant identified Punjabi as the first language spoken at home, and another spoke a combination of Spanish and English in her home. (See Table 2.)

Table 2.*Demographic Variables of the Participants*

No.	Age at time of research	Age at diagnosis	Age at end of treatment	Birth order* of well-sibling	Age of sick-sibling at diagnosis	Gender of sick-sibling	Diagnosis
1	20	9	12	1 of 2	4.5	M	Rhabdomyosarcoma
2	20	10	13	2 of 3	3.5	M	Leukemia
3	21	11	14	1 of 2	7	M	Leukemia
4	26	15	16	2 of 3	18	F	Unknown
5	29	10	12	2 of 2	13	F	Acute Lymphocytic Leukemia
6	29	12	13	1 of 3	4	F	Wilms' Tumour
7	30	17	17	1 of 2	14	F	Thyroid Cancer
Mean	25	12	13.9		9.1		

*Birth order: 1 of 2 indicates eldest of 2 children, 2 of 3 means the middle child of 3, and 2 of 2 means second born of 2.
Abbreviations: F, female; M, male

Data Collection and Analysis

Interview procedure - narrative interview. Rudyard Kipling said, “If history were taught in the form of stories, it would never be forgotten” (as cited by Brayfield & Sprott, 2013, p. 2). When I heard this quote I understood on another level the importance of stories, and the value of using narrative interviews to collect qualitative data. Accordingly, I facilitated my data collection through narrative interviews with my participants. Moustakas (1994) outlines that the phenomenological investigation is usually conducted through an interview format, that utilizes open-ended comments and questions that facilitates conversation between the researcher and participant (p. 114). In collaboration and consultation with my supervisor and my little sister, Jasmine, I worked to develop the narrative interview protocol. (My sister Jasmine also acted as the pilot-participant for the pilot run to help me assess and refine the interview protocol, prompt questions, and streamline my conducting of the interview.) The narrative interview procedure involved the participant telling me what it had been like to be them when their sibling was diagnosed with and treated for cancer. I wanted to give the space to allow the participants to tell their stories while I listened, and to only provide minimal guidance through clarifying questions and prompts if necessary. The essential aim of a narrative interview is to gather a rich and

detailed account of a person's story or lived experience (Chase, 2011), and mostly allows participants' the opportunity to tell their story in its entirety without constraints and restrictions (Riessman, 1993). The co-creating of data that are characteristic of narrative interviews happens with the participant's sharing of his or her story while the researcher practices active listening to encourage the speaker. The researcher co-creates with the participant in the way they engage, listen to, and facilitate the participant's telling of their story (e.g., by asking for clarification, or by using open-ended "what-else" like prompts; Morrow, 2007).

I began my interviews by inviting participants to engage in a *clustering* exercise—a creative writing tool devised by Gabriele Rico (2000). Moustakas (1994) outlined the importance of creating an environment in which the participant feels comfortable to share their story honestly and comprehensively (p. 114). He suggested that a researcher can create such an environment by engaging the participant in "social conversation" or a "brief meditative activity aimed at creating a relaxed and trusting environment" (p. 114). In following Moustakas' suggestions I implemented Rico's clustering technique as a way of inviting the participant into the research space.

Clustering is a technique used "to elicit images and feelings to help facilitate the individual's telling his or her own story" (Karpiak, 2006, p.86). I gave participants a blank sheet of paper, and in the center of the page I asked them to write "What it was like to be me _____ (name) when _____ (name of sibling diagnosed with cancer) was diagnosed with and treated for cancer" in a bubble. I then asked them to attach bubbles and create a mind map from this identity with different phrases, ideas, images, themes, or even drawings if they were so inclined. Clustering is a stream-of-consciousness brain storming activity that allows participants to write whatever comes to their minds about what that time of their life was like for them. The intention

with the mind map was to get them to start thinking about their experience, pulling up different memories, and to help ease participants into the interview process.

I aimed to keep this practice free and open, making it clear to participants that there was no “right” way to engage in the activity. I told them that this was an exercise strictly for their own process, and was not intended as a piece of data I would analyze, but simply as a tool to help them to “drop” into their story by brain storming before they began verbalizing their story. Once they completed this map, I asked them to tell me their story, and told them that they could use the map as a guide to help provide them with topics to draw from as the interview went along. To begin the conversation-like telling of their story to me, I said: “Okay, now that you’ve had a chance to think back to that time when (name of sick-sibling) had cancer, will you please tell me the story of what it was like to be you (name of participant) when (name of sick-sibling) was diagnosed with and then treated for cancer? You can start your story anywhere, I am mostly just going to listen to you and will only interrupt you if I need to make sure that I’m following and understanding you properly.” As they told their story I only interrupted to clarify or to encourage them to tell me in greater detail about a specific part of their story. I would also ask from time to time “and what do you think you needed during that time?” to help focus the siblings in considering what their needs were during their experience. I also had with me prompting questions to help siblings if they expressed feeling “stumped” with what to talk about next in their story. Examples of these questions are:

1. What was it like to be *you* growing up in your family before [name of sibling] was diagnosed with cancer?
2. What was it like for you when (name of sibling) was diagnosed with cancer?
3. What did you need at this time?

4. What do you remember about your sibling's illness and treatment?
5. Did you understand what your sibling's diagnosis meant?
6. How did you understand cancer?
7. How did you understand the treatments?
8. How were you thinking and feeling during all this?
9. What were you doing during this time?
10. What was going on in your life?
11. What was your communication like with your brother/sister about their cancer?
12. What was your communication like with your parents regarding your brother/sister's cancer?
13. What about communication with other siblings or family members?
14. What about communication with friends about your sibling's cancer?
15. Did you feel like cancer was talked about openly in your family?
16. What helped you during this time?
17. What could have helped you?
18. What advice would you give to a family who has recently received a cancer diagnosis in regards to thinking about the non-diagnosed?

At the conclusion of the interview I asked my participants, "Is there anything else you would like to say? Do you feel like you have shared everything that you needed to? Do I have at least a little bit of an idea of what it was like to be you during that time of your life?"

After the interview I told my participants that they were welcome to contact me via email or telephone if any extra thoughts arose after our interview. I let them know that I would follow up with them to verify the data I gathered and to get their thoughts about how true the findings

were for them. This is a technique called member-checking, which I will discuss further in the section entitled Methodological Credibility.

The 7 interviews took place between March and August of 2014. Three of the interviews took place in person in Vancouver, and one took place in Victoria. The remaining 3 interviews took place over Skype with participants who were unable to meet in person due to scheduling or geographical limitations (e.g., one participant was living outside of Canada). Most of the interviews lasted around 1-1.5 hours, but one lasted for 2.5 hours.

Interview and data transcription. Braun and Clarke (2006) emphasize the importance of the researcher familiarizing themselves with their data. I had conducted my research interviews personally and believed that I was already well acquainted with my data. However, Braun and Clarke also assert that not only should the researcher *familiarize* themselves with the data, but they should fully immerse themselves in their data in order to understand the breadth and depth of the content. Upon reflection, I see now that while I initially thought I was immersed with my data by doing the interviews, it was not until I started transcribing that I fully immersed myself “in it.” On average each transcription fully typed out in single spaced formatting was 20 pages long; in total I had 144 pages of transcriptions.

Bold (2012) suggests that the transcription process and how the researcher organizes and transcribes their data will impact further analysis (p.121). Therefore, it is of great importance that the researcher takes specific and attentive care in how they type out the words and include nuances. In regards to this need for attentive care, I recognized that my own social constructivist lens would unwittingly influence my transcribing and “hearing” of the data. As a social-constructivist I assume that all data and knowledge generated in the research interview is co-constructed between participants and researcher (Morrow, 2007). To best capture my

participants' stories and add to the credibility of my study, I chose to transcribe the interviews verbatim: I wrote down every word of dialogue I heard, including filler words like "ums, ahs, like." I also used underlining to show when I heard a participant specifically put stress on a word. I separated words into syllables when a participant stretched out a word for emphasis, for example "trau-ma-tizing." I used brackets to include context such as observations I had made while interviewing, for example [participant gets teary], and descriptor words when I heard in the recording that a participant got emotional, for example [participant starts crying]. Because I transcribed interviews verbatim, I included dialogue when outside "noise" distracted one or both of our attention away from our conversation. An example of this was one day when I was interviewing a participant and there was mama duck with four baby ducks that would continually appear in the pond outside the window of the research interview office. While obviously the ducks were not part of my analysis, I do think this type of interaction was important to include in my transcription. I believe it showed a familiarity between us, as she would remark "oh there they are again!" and we both would look and giggle at the ducks. Similarly, if I had chosen to interrupt her and say, "listen, you really must focus on telling me your story," I think it would have been important for me to transcribe this reaction. Perhaps afterwards if I reflected back and found my participant was not feeling safe in the interview, I might have read this and seen I was dismissing her.

An interesting side-note on transcribing all "ums, ahhs, and likes" is the impact this had on at least some of the participants. One participant reported to me that she felt uncomfortable reading her verbatim transcript, not because of the content of what she was talking about, but the amount of "umms and likes" she used in her language. I assured her that these types of utterances are very normal in everyday speech. However, in honouring her voice in the creation of her

story, she chose to edit some of her dialogue so that she would sound, in her words, “more intelligent on the written page.”

Analyzing the data. To analyze my data I applied thematic analysis to the narrative interview transcriptions; that is, I coded the data so as to generate themes that I developed from the data and through the analytic process. By using thematic analysis, I engaged in a searching process where I searched across the entire data set looking for recursive units of meaning that thematically coalesced to bring organization and coherence to the data collected. A theme reflects a “repeated pattern of meaning” (Braun & Clarke, 2006, p. 86) that is found either within or across participants. This allowed me to describe and summarize the data in rich and thick detail. Braun and Clarke argued that thematic analysis is a method that is essentially independent of theory and epistemology and can be applied across a range of approaches; therefore it is appropriate that I applied it to my narrative data collected for my phenomenological study of the sibling lived experience of cancer and what needs they experienced during this life event.

Approaching the thematic analysis of the data. Braun and Clarke (2006) outlined five critical choices a researcher should consider before and during thematic data analysis. Using Braun and Clarke’s outline, the choices I needed to consider were: (a) What and how will I decide what counts as a theme? (b) Do I want my research findings to give a rich description of the entire data set, or a detailed account of one specific aspect? (c) Will I work inductively or deductively/theoretically to identify themes? (d) At what level do I wish to identify themes: semantically or latently? (e) As the researcher, what epistemological beliefs—will I bring to this study—essentialist/realist or constructionist? In respecting Braun and Clarke’s recommendations, I will next address each of these five questions or choice-points, and how I approached my analysis.

What and how will I decide what counts as a theme? I defined a theme using Braun and Clarke's (2006) criteria of relevance and prevalence. In terms of relevance, a theme is, "something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set" (p. 10). To this end I kept my research question constantly in mind as I was analysing my data, coding and considering themes. I always had to ask myself, "is this theme answering the research question?" To assist in my remembering of this I posted a sticky note on the desk where I work with my research question written on it, so I could stay focused.

Braun and Clarke (2006) also discussed the prevalence of the theme, and how to determine when the theme's prevalence is considered substantial enough to conclude "themeness" or propose another theme (p. 25). Their guidelines for establishing prevalence say that there is not a right or wrong method for determining prevalence, and that no current standard exists for the number of participants whose data contribute to a theme, but that consistency and "keyness" (p. 82) are essential. That is, once you decide what qualifies as a theme—stick to it. In their discussion they provide an example and description of prevalence in a study that noted if the *frequency* of a pattern of response was such that it appeared between 2 or 22 times *across the data*, prevalence could be considered sufficient to say that the pattern of response reflected a theme. In other words, frequency, and keyness of a pattern or response across the data set is what determines prevalence.

A second suggestion by Braun and Clarke on how to approach the question of prevalence required to establish the presence of a theme, was to focus on the *representativeness* (or commonality) of the pattern of response *across participants*. In some cases, said Braun and Clarke, researchers have employed 60% as an arbitrary cut-off number of participants to reflect a

majority providing thematically-consistent data. In other words, if the pattern of response is provided by more than half of the participants, then we assume the presence of a unifying or common pattern across participants in the sample. For example, in my study with 7 participants I could determine that a finding of a similar response pattern in at least 4 of the 7 participants (i.e., 57% endorsement rate) is sufficient to conclude it a theme. The definition (and operationalization) of a theme is something that captures an important meaning or patterned response in relation to the research question (Braun & Clarke, 2006). As such, I decided it most reasonable (in the sense of trustworthiness and applicability, or “reliability”) that should a response pattern appear more than 4 times across participants, it would be considered for a theme or subtheme in my study. For example, if one participant spoke about feeling a need for attention from their parents, and three other participants echoed a similar sentiment, “attention-from-parents” became a possibility for a theme or subtheme. When a response pattern arose that did not meet my 57% endorsement rate criterion for a theme, I did not consider this response pattern a theme. However, I did not discount these data as unusual or invalid. Rather, I noted them as auxiliary findings, which I discuss in my discussion chapter. Due to the time constraints and feasibility of this being a graduate level research project, I could not work to reach data saturation.⁵

Do I want my research findings to give a rich description of the entire data set, or a detailed account of one specific aspect? My research aim was to learn about the needs of siblings, and therefore my focus was on providing a specific “detailed account of one particular aspect” (Braun & Clarke, 2006, p. 11) of the data set. In coding the data, I worked to be alert and open to noticing patterns of responses or units of meanings relating to the needs of siblings that I

⁵ Data saturation implies that enough stories have been gathered that themes start repeating themselves and added information does not add new understanding about the phenomenon being explored (Kirby, Greaves, & Reid, 2006).

found within the data. Specifically, I aimed to bring a narrow focus to my thematic analysis of the data by being open to, attending to, and describing the needs of siblings as opposed to providing a rich description of the full experience of being an adolescent sibling of a child with cancer. An example of something that was a part of the interview but not relevant to the specific aspects I was looking at, was the detail one participant shared about her experience of having another sibling who had a different life threatening illness. This being the case, to identify themes from my data I analyzed and coded my data using an inductive (bottom up) approach. I did this while remaining cognizant of my knowledge of the extant theoretical, definitional, and empirical literatures on the sibling experience of childhood cancer and of human psychological needs.

Will I work inductively or deductively/theoretically to identify themes? Stepping back momentarily, I think it is important to remember that theoretical/deductive thematic analysis is driven by the researcher's conceptual *and* theoretical interest in the area. This is opposed to the inductive approach in which themes are conceptually developed without trying to fit the data into a pre-existing theoretically-derived coding frame (Braun & Clarke, 2006). I was specifically invested and interested in exploring and understanding the lived experience and needs of adolescent siblings of children with cancer. Braun and Clarke reported that it is difficult for researchers to completely free themselves of their theoretical lenses. What they mean by this is that even for the researcher who claims to only be inductively identifying themes, their theoretical lens still influences how they report the "voice" of the participant. Therefore, what I hear, and how I report the data is influenced by my theoretical lens. That said, my intention was to remain inductively open to the presence of needs that were perhaps not adequately conceptualized by or contained within existing need-based psychological literature or the

literature on the sibling experience of cancer. My approach to coding was both inductive and deductive/theoretical. I worked to be as consciously reflexive as possible in this process. I adopted a participant-observer approach; I continually asked and checked that I was leading my reading, hearing, and coding of the data with an inductive eye, ear, and mind. I then compared and contrasted this information with my existing knowledge. I believe this mixed-inductive/deductive approach is true to my philosophical or meta-theoretical perspective of social constructivism.

At what level do I wish to identify themes: semantically or latently? Semantically identifying themes means describing themes for their explicit and surface level meaning, or letting the data speak directly for themselves (Braun & Clarke, 2006). When a researcher codes semantically they look for what is explicitly stated by participants and nothing more. For example a participant who stated: “I needed more attention” would be semantically coded as a *need for attention*. In contrast, latently identifying themes requires the researcher to interpret the data and “read between the lines.” When themes are analyzed or interpreted they are identified at a latent level with the aim to theorise or explain the patterns and provide larger meanings or effects (Braun & Clarke, 2006). Latent themes require the researcher to examine ideas, assumptions, conceptualizations, and ideologies that are inferred (p. 84). For example, my participant Bree stated that she needed to, “get asked to see ‘how you’re doing?’ or encouragement for me to grow, instead of it just being about the pain that is happening.” “I coded this on a semantic level, using the codes “need to be asked how I’m doing” and “need for encouragement.” Later on in the analytic process, it became clear to me that these two codes were subsumed within an overarching latently-coded theme that I labeled as the *need for acknowledgment and attention*. I believe the semantic coding of this would have been too surface

level, and would not get at the core need for acknowledgement. One important intention behind my study was to provide siblings, parents, medical professionals, and the general public with information that is clear, memorable, applicable, and relatable. I thought that moving from semantic-level coding to latent-level themes would best serve this intention, and accordingly, I chose to code on both semantic and latent levels.

As the researcher, what epistemological beliefs will I bring to this study-- essentialist/realist or constructionist? While the terms “constructivism” and “constructionism” are often used interchangeably in the literature (Young & Collin, 2004), Braun and Clarke (2006) appear to use the term constructionism when reminding their reader that constructionism posits “meaning and experience [as] socially produced and reproduced, rather than inhering within individuals” (p. 12). In contrast, constructivism, as I wrote about earlier in this chapter, extends and involves itself with understanding the internalization of socially created knowledge and meaning by way of cognitive processes and mental constructs (e.g., schema, internal working models), which the individual uses to explain his or her experience. By considering Braun and Clarke’s five questions before and during my research I had a solid reference point for referring to as I considered how and why I was analyzing my data.

Conducting the thematic analysis of the data. Braun and Clarke (2006) next outline six phases of thematic analysis, which I utilized to analyze my data. These six phases are: (a) familiarizing yourself with your data; (b) generating initial codes; (c) searching for themes; (d) reviewing themes; (e) defining and naming themes; and (f) producing the report. I followed this guideline closely and carefully. As I mentioned earlier regarding my transcriptions, I attended to ‘familiarizing yourself with your data’ by the fact that I interviewed all 7 participants and completed the verbatim transcribing of the narrative interview data. After completing

transcribing of all the interview data, I applied Braun and Clarke's concept of 'repeated reading' of the data so as to be fully immersed and well versed in my data. This means I recursively read the data in an "active way" while developing themes, patterns, and meaning (p.16).

After I had read and re-read my transcriptions, I started labelling what I called initial "hunch" codes I believed I was hearing/seeing in the data. I brought these to my supervisor to discuss with her what I thought I was hearing/seeing. From our meeting, she provided me with questions and a process of inquiry to go back to the data and *generate my initial codes*. I highlighted, searched, and identified supporting quotes for the codes I found and which I thought I was hearing/seeing in my document. As a visual learner and creative person, I wrote out the different codes I was developing using headings "preliminary codes" and "final codes" (Braun & Clarke, 2006, p. 17). An example would be coding an excerpt in which the participant described a funny memory and the feeling of relief after this. I initially coded this with the preliminary codes of: hospital, laughter, fun, funny, humour, silly, relief, emotion, after which I settled on the final code of laughter.

Once the codes were formulated I shared them with my supervisor again and then began *searching for themes* through finding connections between codes. For example, anger was a prevalent emotion reported and discussed by participants. Yet at the same time, I recognized that often accompanying the narrative around having felt anger, were the remembered-feelings of guilt for feeling angry. There was also a prevalence of uncomfortable thoughts that well-siblings had that they judged as "bad" or embarrassing, such as thinking their sick-sibling was ruining the family. Thus began a discussion around how to describe this experience of siblings, and if this lived experience reflected a need of sorts. I discussed this at length with my supervisor, a fellow researcher, and my sister. This is a task that Braun and Clarke (2006) endorsed for solo

researchers. Together we queried and wondered if participants were getting at or implying a need for siblings to know that they can give themselves permission to feel the initial emotion and thoughts without judging them? Or, was it a need for validation that these were normal emotions and thoughts under the circumstances? In the end through much discussion we called this theme *The Need to Know that it is Normal to have Difficult Emotions and Uncomfortable Thoughts*.

This process also involved checking to make sure that the themes were answering the research question, were accurately reflected across the data, and also were not redundant. In terms of redundancy, I collapsed some earlier-considered themes into one theme when it became clear that both themes were saying or capturing overlapping ideas. An example of this was that I had labelled *the need to be acknowledged* and *the need for attention* as two separate themes. Through much discussion and deliberation with my supervisor and in consultation with my sister, it was decided that the need for acknowledgment and attention could, and should, be folded together, as they were needs that were both resolved through similar action—attention.

The next process of *defining and naming themes* was at times difficult and frustrating. I have a perfectionist attachment to words, and as a social constructivist I was sensitive to the language that I was choosing to represent these themes. I wanted the language to be reflective and descriptive of the siblings' language and the needs I believed I heard the siblings articulating. Further, I wanted the themes to be accurate representations of what participants experienced, and in this way, to reassure them that I had heard their lived experience. I also wanted findings to honestly inform others about the needs of siblings. Most of all, I wanted my naming of themes to render them self-explanatory. For example, in my exploration with language and formulating my themes, I struggled with how to label the need for acknowledgment because acknowledgment is associated with attention. However,

acknowledgment was a term that I was invested in. The reason for this was that I heard each participant speak to their desire to be asked how they were, to be seen or recognized in the process of their sibling's illness. This theme was so strong and prevalent across participants, I thought that labelling it under the need for attention would negate this quality of acknowledgement. Yet, having the need for acknowledgement and the need for attention as two separate themes was clearly redundant. Therefore we decided to call the theme *The Need for Acknowledgment and Attention*.

Through this iterative process of solidifying my themes by defining and naming them, I wrote a narrative summary about each theme and provided these together with salient quotes to participants. This was the process of member checking in which I asked for their feedback in assessing the representativeness, relevance, or fit of each theme for them. I emailed participants and specifically asked them to review the preliminary findings and say whether the themes and quotes accurately represented their lived experience or whether they would like some changes to be made. Member checking is an essential task in developing trustworthiness and credibility for the research.

Qualitative Methodological Trustworthiness

The positivistic concepts of reliability and validity are referred to and described differently within qualitative methodology. Quantitative reliability and validity are concerned with whether a study develops meaningful and useful inferences from the results and that it is faithfully repeatable in what it attests to be measuring (Creswell, 2009, p. 149). Indicators of qualitative trustworthiness are less standardized and consensually agreed upon than are quantitative formulations of reliability and validity. As one well-cited example, Krefling (1991) outlines four specific constructs to be considered in qualitative research to give rigor and

trustworthiness to the research. These are: credibility, transferability, dependability, and confirmability. Krefting developed these constructs and associated strategies based upon the work of Guba (1981) and Lincoln and Guba (1985).

Credibility

Research is deemed credible when it holds a certain truth-value, which means that the researcher feels confident they have captured the “truth” of participants, that it is an accurate representation (Pyett, 2003). Therefore, this truth is not determined a priori, as in quantitative methodology, but is participant-oriented (Sandelowski, 1986, as cited by Krefting, 1991). My task was not to summarize and condense the sibling experience into one generalizable reality, but rather to acknowledge that 7 realities would contribute to this research, and that these 7 realities required trustworthy re-presentation. To demonstrate the credibility and “truthiness” (Bruner, 1988, p.708) of a study, researchers use strategies such as: member checking, prolonged engagement, reflexivity, and peer examination (Creswell & Miller, 2000; Krefting, 1991). In this next, section I discuss the credibility of my research by discussing how I used each of these strategies.

Member Checking. Perhaps the “the most crucial technique for establishing credibility” (Lincoln & Guba, 1985, p. 314) is that of member checking. Member checking is a process whereby the researcher takes the data and interpretations back to participants for their approval and confirmation of findings (Creswell & Miller, 2000). Member checking ensures that participants’ stories are accurately captured and that themes are congruent with participants’ stories, to the extent that (most) participants resonate with the thematically represented findings of the study. Member checking also gives participants a chance to volunteer additional information. I engaged in member checking with my participants several times during the course

of data analysis through email. One of the first times I checked in with my participants after data collection was regarding the use of the word “survivor” in my thesis, because one of my participants shared that she did not like using this word. I used member checking to ask other participants how they felt about the use of the word survivor, and then made the decision to omit it from the title of my thesis. I will discuss this in more detail in my discussion chapter. The second way in which I engaged in member checking was when I sent participants the themes I had developed from our interviews. These themes were presented with a brief explanation together with supporting quotes I extracted from the verbatim transcripts. At the end of each theme I asked participants if I had accurately heard and captured their stories. I asked them if they agreed or disagreed that the theme and quotes I had provided accurately depicted at least one part of the cancer experience for them, the well-siblings who had a sibling go through cancer treatment. I provided them with an option to select *agree* or *disagree* and then space to provide feedback and commentary.

Krefting (1991) described the importance of time spent developing researcher-participant relationship in order to add to credibility, what Lincoln and Guba (1985) called “prolonged engagement”. While my face-to-face time with participants was limited to one interview I tried to develop the familiarity between us from our first conversation, which was the screening interview, and throughout follow up emails and phone calls. To this same quality Krefting warned that credibility can also be threatened when researcher and participants become too close, thereby causing participants’ data to be based on social desirability (Kirk & Miller, 1986 as cited in Krefting, 1991). Regarding this, I thought it was of particular importance not to disclose to participants that I had had cancer, and I will speak more specifically to this point under ethical considerations and reflexivity. Further to this point of navigating healthy boundaries between

participant and researcher, is the importance for the researcher to not become “enmeshed”⁶ with participants. Enmeshment can cause the researcher to have difficulty interpreting findings, therefore not becoming enmeshed is important so that the researcher can separate their own experience from that of the participants (Marcus & Fischer, 1986, as cited by Krefting, 1991). Reflexivity is another credibility strategy, which will help maintain differentiation between participants and researchers (Krefting, 1991).

Reflexivity. Assessing the influence of my background, values, perceptions, assumptions, experiences, and interests in regards to the research study, is essential to adding credibility to my study, and it is an ethical consideration (Guillemin & Gillam, 2004). According to Sandelowski and Barroso (2002), “Reflexivity implies the ability to reflect inward toward oneself as an inquirer; outward to the cultural, historical, linguistic, political, and other forces that shape everything about inquiry; and, in between researcher and participant to the social interaction they share” (p. 222). By clearly identifying and telling the stories of my own background, outlining my intentions and the purposes of the study, and by consistently returning to the data, I remained reflexive and openly addressed how my own story and inevitable biases would influence my analysis and interpretation of participants’ narratives (Butler-Kisber, 2010; Clandinin & Connelly, 2000; Creswell & Miller, 2000). Schreiber (2001) was firm in her claim that the credibility of findings rests in the imperative for the researcher to “recognize and constantly challenge her or his personal theories and biases against the data” (p. 61). Reflexivity is a more active form of reflection. Reflexivity is an ongoing dialogue and formative checking-in with oneself about how life experiences, biases, values, and what Schreiber called “personal theories,” interact with and shape not only the data collected, but also analyses and sense-making of the

⁶Krefting described “enmeshment” through citing the work of Marcus and Fischer (1986), whereby the researcher becomes overinvolved with the participants’ story, thereby losing sight of their own experience, boundaries and interpretations. When the participant’s experience becomes the researcher’s experience.

data. Using relationships is another strategy for reflexivity and one that I used and discuss further on.

Guillemin and Gillam (2004) asserted that *reflexivity* is not only important for issues of credibility, but also for upholding ethical responsibilities. In navigating the relationship between researcher and participant, a high degree of reflexivity is necessary to be sure to respect the autonomy, dignity, and privacy of participants, and to do no harm (Guillemin & Gillam, 2004). Due to my professional and personal experience with cancer and well-siblings, I believe reflexivity has been an important ethical consideration in the research process of this study. In order to remain aware and cognizant of the ways in which my beliefs and personal experiences might have impacted my research, I kept a researcher's journal that included a careful journaling of my own processes, thoughts, and reactions. I also engaged in memoing and I kept a record of email communication between my supervisor and myself from questions and queries I had during recruitment and data collection. Journaling was particularly important for me; because the subject matter was so close to my heart, I needed to engage in reflexivity to stay grounded and present in the process, and I used journaling for this end. Chase (2011) said reflexive practice helps a researcher to reflect and "interrogate their assumptions" and "experiment with interpretations" (p. 69). I was intent on "interrogating [my] assumptions" and "experiment[ing] with interpretations" as a way to do due diligence to ethical considerations further to those requested and required by my university's Human Research Ethic's Board. I felt so strongly about the ethical considerations and assumptive implications of my status because I am a researcher who (a) recovered from childhood cancer, and also (b) had a younger sibling who was impacted by my cancer diagnosis.

I believe one of the first ways I “interrogated” my assumptions was when I started asking what it was like for Jasmine to be Jasmine when I had cancer. I had made assumptions that I knew what the cancer experience was like because I had lived my version of it—but I had not lived Jasmine’s experience. This was an ongoing investigation, and came up time and time again. For example, I had assumed and interpreted from Jasmine’s stories that her transition into Grade 8 was particularly difficult because she was at a school that I had just graduated from, and the teachers had known me personally and all knew that I was now sick. I thought this was hard for her because they knew me, but did not know her, and were therefore asking her questions about me, giving her unwanted attention. This was an incorrect assumption that she corrected me about as I shared my thesis with her. She said her uncomfortable experience at school was more about her own social-anxiety going into a new high school, being bullied, and experiencing feelings of loneliness. These experiences and the anxiety she felt were further exasperated because she believed she could not ask for help, lest she be a burden on her family that was stressed with the reality of my cancer diagnosis.

This was a good awareness to carry forward into my research about the stories I had told myself. I vowed to continually check-out and experiment with interpretations through reflexive practice. My research is based upon the assumption that well-siblings have needs, and thus I went into the research with this assumption in mind, and it was present as I analyzed the data. It was my intention to stay true to the stories of the participants, and hence the reason that member checking was so imperative, so they could confirm or deny whether a need was true for them. This would be an example of experimenting with interpretations, being curious about how I heard the needs in the research interviews, and if I heard them correctly. I do believe I was open to hearing if a participant said to me “no, I had no particular needs” because there was one

participant who, in some cases, did not agree with a need I presented. I believe I was able to adequately “interrogate my assumptions” and “experiment with interpretations” through self-reflection and awareness, by chatting with my own sister, and through reflective journaling. As Haverkamp and Young (2007) asserted, “qualitative research is characterized by the awareness that the researcher is pursuing understanding, is an interpreter rather than a reporter” (p. 276).

Expanded ethical considerations. Another crucial ethical consideration for me was to consider my own experience of having lived through cancer. Only one of my participants knew that I had had cancer, and that I had a sibling who had been an adolescent at the time of my diagnosis and treatment, and who was impacted by the experience. The reason being was that this participant knew me prior to being a part of the study. As I write this now, I wonder what it will be like for my participants to realize through reading my thesis that I had cancer. This decision was made with great consideration. I discussed this point several times with my supervisor. I respect my participants and hope that they do not feel betrayed by not knowing. It was an ethical and purposeful decision to not openly disclose that I had been sick with and lived through cancer. My plan was to share only if they specifically asked me if I had had cancer, or if I had been the adolescent sibling of a brother or sister with cancer. My reasoning was that this research was about their story, the story of the well-sibling, whose story and experience were likely often neglected for the experience of their sick-sibling. I wanted the focus to be on the participant alone. In the end none of my participants specifically asked, though one did inquire why I was interested in this population. I said that I had been inspired by my work at *Camp Goodtimes*, and did not elaborate further. However, I was fully committed to disclosing should a conversation have arisen.

It was my rationale that if participants were to have had this knowledge before or at the time I did their interviews, I believed it could have impeded their comfort in telling me their stories and impacted the data; and, this would have affected data credibility (Kirk & Miller, 1986 as cited by Krefting, 1991). My concern was that participants may have edited what they wanted to express in an attempt to take care of or protect me from the truth of their experience, and I did not want to burden them with this. I wanted to hear their stories and their honest truth about what it was like to be them during their sibling's cancer. In sum this research was not about me, it was about them.

In honouring my belief that this research was a co-construction with my participants, it was also important for me to acknowledge that the interview process was likely to have an effect on me too. As Bold (2012) said:

If the storytelling process has an impact on the teller, then it seems safe to assume that there will be an impact on the listener, albeit a different one. All participants may have their lives changed in some way by the shared experience. (p. 23)

Accordingly, I prepared myself mentally before each interview so that I could remain present for my participants if I was triggered by their stories. There were times where siblings' stories were very close to that of my little sister's, and these caused an emotional response within me. In my graduate-level training as a counsellor, I have learned the ability to compartmentalize when I am triggered by a client, so that I can deal with my own reactions and remain present for whoever is sitting in front of me. For me, compartmentalizing is not a denial of an internal emotional reaction, but rather a skilled and mindful practice of noticing and mentally acknowledging my emotional reaction while grounding myself and practicing reflective listening. I believe that I am skilled at doing this, specifically within the cancer culture because of my experience of working

at *Camp Goodtimes*. In my work at camp, I had the privilege of meeting over 500 people each summer whose lives were, in one way or another, impacted by cancer. I believe I was effectively able to remain present in my job at *Camp Goodtimes* and in my ongoing work as a counsellor, by maintaining a bounded internal response through the practice of compartmentalizing. This does not mean that I was emotionless when a participant in my research study shared a particularly painful or meaningful memory. Rather, that my reaction was a way to join with them in validation of their experience, not about me going off and engaging in my own story. Through this mindful practice I would also make note to spend time reflecting on my reaction in my own time when it was professionally appropriate, through debriefing with colleagues and privately with my family and own therapist. This practice and these conversations allowed me to remain present both to participants during interviews, and to the data during transcription and analysis.

Another practice that kept me present during the research process was my self-care. For example, I mentally prepared ahead of each interview (by intentionally writing in my researcher's journal), I took breaks during transcriptions and coding (by going to the gym and getting fresh air), and I sought out therapy around my relationship with my cancer and my little sister. In talking to another friend who also lived through childhood cancer, she asked me if being the researcher caused me to feel guilty for having an illness that I could not help having. My intention with this research was (and remains) not to place blame or guilt on anyone—the sick-sibling, the well-sibling and any other family member—for the ways in which they did and did not behave during their cancer experience. My intention was to offer a safe space of empathic acceptance, for both my participants and myself, so that they could tell their stories and share their experiences; and so that I could learn and listen without judgment of them or myself. I could not have had this peace, and done this research if both my own relationship with cancer

and my relationship with my sister were not healthy. When I first recognized the impact the cancer experience had on Jasmine I felt responsible for how she felt. However, through exploration and healing with Jasmine I have let go of the guilt. This is not to say, however, that I used this research as a tool to fix our relationship. Instead, I used our relationship and Jasmine's courage, authenticity, and articulateness to further learn and understand about the lived experience of well-siblings. I withheld judgment, and instead evoked an air of curiosity and compassion for Jasmine, the sibling experience, and myself. I carried this air as I explored the literature, research process, and the other sibling experts I came into contact with. Therefore, while the subject matter still pulls at my heartstrings, it is now not in a guilty way, but in a compassionate way for both my sister's experience and my own. While I feel sad for how my diagnosis and treatment impacted Jasmine, I do not take responsibility for it.

In sum, reflexivity contributes to the ethical integrity of a study. Amulya (2006) spoke to reflexivity as the way in which personal reflection has the ability to create powerful opportunities for learning, and to provide new insight into experiences. By remaining reflexive, I believe I have been able to infuse my research with passion and my own perspectives, while also being mindful about how I may have influenced my participants, the data I collected, and the findings I report in the next chapter.

Relationships as a strategy for reflexivity. Integral to my reflexivity were the relationships in my life in which I was able to engage in reflexive conversations. These were conversations with my supervisor with whom I felt safe to share both my emotional and psychological reactions. It was also important for me throughout the entire process to stay present to my relationship with my own little sister—the sibling who inspired this thesis (and who acted as consultant to and completed the pilot study interview for this study). I did not

divulge confidential information from my research interviews with my sister. Rather I would check-in from time to time with her about our relationship, her experiences, and sharing my personal reactions to the research experience.

Further to the idea of using outside relationships to help remain reflexive is the concept Krefting (1991) called *peer examination* or, what Marshall and Rossman (2011) called, *peer debriefing*. In peer examination the researcher discusses the research process and their findings with peers who are impartial, yet knowledgeable, about qualitative research (Krefting, 1990; Marshall & Rossman, 2011). Due to the graduate program in counselling psychology that I am enrolled in, I am fortunate to have three peers whom I spoke with regarding my research, all of who are familiar with qualitative methodology through doing their own research. Through debriefing and sharing about the data collection process, as well as coding and thematic analysis, I was able to get different perspectives and also confirmation of, argument against, or clarification on, some of my ideas. This process was not only integral to lending credibility to my study; it was also a form of self-care in making sure that my solo-researcher experience was not a lonely one.

Not separate from but further to reflexivity, Haverkamp and Young (2007) discussed how the collaborative method of qualitative research allows for the 'fusion of horizons' between participant and researcher. A 'fusion of horizons' is a credibility construct that occurs when the researcher and participant develop (and agree on) a new understanding of the phenomenon in question through the collaboration of each of their individual horizons (views). It seems to me that Haverkamp and Young might even be suggesting that the fusion of horizons between a researcher and participant is the most robust indicator of trustworthiness and credibility. They say that it is one step further than reflexivity. In 'fusion' the researcher not only practices self-

awareness of their own perspectives, values, and biases, but they actively broaden this perspective to meet that of their participants. The goal in this ‘fusion of horizons’ is a new understanding of the phenomenon in question (p. 276). The question of course is how to establish and assess “the degree to which one achieves a ‘fusion of horizons’” (p. 278)

Haverkamp and Young (2007) described a research study by Beckstead and Morrow (2004) in which the researchers openly disclosed their assumptions and viewpoints of the research study they were embarking on, and disclosed how they realized their perspectives would probably be very different from many of their participants. To expand beyond reflexivity they not only engaged in memoing and journaling through their research, but also employed the participants in a focus group in which they were asked to check Beckstead’s biases throughout the research process. Further to this, Beckstead and Morrow also had a group (3 people) of peer researchers to help them with second-readings and revision of the research. All of these components helped them to attain the quintessential moment of ‘fusion’ according to Haverkamp and Young. This moment of fusion occurred when the researchers were analyzing the data and engaging in member checking and the participants were opposed to the way the data were being categorized—and the researchers listened. Their argument is that this fusion is much more than engaging in reflexive activities, it is the creation of meaning through the new understanding that occurs between the participant and researcher. I wonder then, if, and in what ways, I created a ‘fusion of horizons’ with my participants. I think it is possible I achieved a ‘fusion of horizons’ in the way I let go of the word survivor, and that this form of member-checking is an unheralded strategy for the fusing of horizons. I also think it is possible I achieved a ‘fusion’ by continually conversing and asking my sister for her expert opinion (as a sibling but not participant in the study).

Transferability

Transferability, is the qualitative counterpart to the quantitative validity construct of generalizability. It can also be described as applicability; how is this study able to be applied to others who may have stories similar to the participants in the research study (Krefting, 1991)? Or as Butler-Kisber (2010) described “particularizability” in which the study “shows rather than tells in compelling and helpful detail the particulars that subsequently will be useful for thinking about similar situations or contexts” (p. 46). Transferability is a strategy that not all researchers aim for, as some seek only to provide a rich description of the phenomenon, and nothing more. I, however, do hope that my research will be transferable, particular and accessible to other well-siblings, who will be able to see and hear themselves through the stories of other well-siblings. One way I hope to strengthen the transferability of my research is through the knowledge mobilization project You Matter, which I will speak to further in Chapter 4 under the heading “Insights and Implications.” I also hope that this research will be a helpful contribution to the growing body of literature about the needs and experiences of well-siblings. In order for my research to be transferable it was necessary for me to provide a rich amount of particular detail and information regarding my participants and the research process, so others are able to assess for themselves whether or not the findings are transferable (Krefting, 1991). According to Lincoln and Guba (1985), the issue of applicability can be considered addressed so long as the original research has supplied subsequent researchers with enough descriptive data to allow comparison (as cited in Krefting, 1991).

Dependability

The consistency of a study’s findings lends to the dependability of the research, the qualitative construct similar to reliability in quantitative research (Krefting, 1991). In order for

my study to be dependable, I must provide the exact methods of data gathering, analysing, and interpreting, which I have done throughout this methods chapter. However, regardless of how many exact details another researcher might follow to replicate my study, they are unlikely to arrive at the exact same findings as me, and that is not the intended point of providing these details. Qualitative research is acknowledged to be a co-construction where there will be variability from researcher to researcher, and participant to participant. Further to this, as Riessman (1993) discusses, researchers cannot directly access another individual's experience, but can only give a representation of the experience through their own constructed interpretation of what has been co-constructed. Therefore every researcher's own lens of interpretation will influence the data and their analysis. Similarly, when considering the constructivist lens of multiple realities, the aim is not to condense and take the average of an experience, omitting outliers, but rather to include the varied perspectives of all (Krefting, 1991). What makes my study dependable is the fact the variability within my study is what Guba (1981) described as "trackable;" I documented and have provided detailed descriptions and information throughout (as cited in Krefting, 1991). To further the dependability of the study, Krefting (1991) also suggests the use of peer examination to assess the research plan and implementation, which I spoke about in the credibility section.

Confirmability

Data are considered to be confirmable when they have neutrality (Guba, 1981). Neutrality assumes that the data are the truth of the participants, and the data are considered confirmable when this truth of the participants is considered to have applicability to people outside the research study (Krefting, 1991). As I have previously stated, I followed several steps to assure both the credibility/truthfulness of the data as well as transferability. Krefting (1991) supported

that reflexivity also contributes to confirmability in that the researcher continually remains aware of their influence on the data. Guba (1981) suggested that by having two sources for each theme, confirmability was also strengthened. To lead to further confirmability I provided more than two data extracts for every theme that I identified.

In conclusion, in striving to ensure the rigor and trustworthiness of my study and findings, I relied heavily on technical literature (e.g., Braun & Clarke, 2006; Krefting, 1991) and on previous peer-reviewed studies of the sibling experience (e.g., Wilkins & Woodgate, 2005) for recommendations on how to conduct my research. Wilkins and Woodgate's (2005) review of previous qualitative studies was a particularly helpful reference point for my study. In noting the imperative for researchers to "conduct qualitative research that focuses on constructs and themes central to the sibling experience of childhood cancer," Wilkins and Woodgate suggested utilizing "qualitative research designs that best capture those constructs and themes" and to provide "detailed descriptions of the research process"(p. 317). To this end, and as I previously outlined, I designed my research as a qualitative phenomenological study, using narrative interviews and thematic analysis as my data collection and analytic methods, respectively. I was also conscientious about the trustworthiness and credibility of my research by scrupulously engaging in the strategies and guidelines as provided by Braun and Clarke, (2006), Guba (1981), and Krefting (1991).

Chapter Summary

I conclude this chapter by acknowledging the multi-faceted complexity of qualitative methodology, and my firm belief that I have developed, designed, and implemented a trustworthy study as per the guidelines presented by Krefting (1991) and Guba (1981). In this chapter I have described qualitative research along with my philosophical location and ethical

considerations. I outlined the design of my study and my chosen research methods for collection and analyzing: narrative interviewing and thematic analysis respectively. I also provided the demographics and recruitment details regarding participants and the trustworthiness criteria as it applies to qualitative research.

Chapter 3

Findings

In this chapter I present the thematic findings that answer my research question: What are the needs of adolescents who had a sibling who was diagnosed with and treated for childhood cancer? The 7 need-based themes identified from the narrative interview data were: (a) The Need for Acknowledgement and Attention; (b) The Need for Honest an Open Family Communication; (c) The Need for Inclusion in the Family during Treatment; (d) The Need to Know that it is Normal to have Difficult Emotions and Uncomfortable Thoughts; (e) The Need for Instrumental Support; (f) The Need to Just be a Kid; and (g) The Need for Humour, Laughter and Light-heartedness. I describe and provide verbatim quotes drawn from the interview data, which serve as operational examples, for each theme. I considered 2 themes to include subthemes. Namely, *The Need to Know that it is Normal to have Difficult Emotions and Uncomfortable Thoughts* (Theme 4) subsumes the subtheme, *The need for support exclusively for well-siblings*; and *The Need for Instrumental Support* (Theme 5) subsumes 3 subthemes: (i) *The need for support from family and friends*; (ii) *The need for support from schoolteachers and other adults*; and (iii) *The need for family-level support from helping professionals*. Please note that some participants asked for anonymity, therefore the names included in the study include both pseudonyms and birth-given names.

Findings: Seven Themes

Theme 1: The Need for Acknowledgment and Attention

Six of the 7 participants expressed a remembered need for acknowledgment and all 7, for attention. Participants articulated that they needed to be acknowledged, respected, and seen for who they were and for how they were doing during their sibling's diagnosis and treatment. In

other words, siblings needed confirmation and affirmation of their being. This is in opposition to how they remembered sometimes feeling during their brother or sister's cancer diagnosis and treatment: peripheral, invisible, unimportant, incidental, or a burden. Acknowledgement was needed from parents, extended family members, teachers, friends, professionals, and members of their community. To acknowledge means to openly accept, admit, recognize, or affirm the existence of a fact (Merriam-Webster, 2014); in this case, the existence of the well-sibling's being. The sense of feeling acknowledged is to feel reassured that one is "seen" or that one continues "to matter." By definition, acknowledgment (or its perceived absence) is communicated either directly through spoken words or indirectly through attention and other forms of nonverbal communication. Giving or paying attention to another is a gesture of recognition that communicates the attention-giver's interest in, or awareness, mindfulness, or noticing (Merriam-Webster, 2014), or "seeing" of the other. Bree, for example, reflected, "Like I guess just to get asked to see 'how you're doing?' or encouragement for me to grow, instead of it just being about the pain that is happening." Emily captured the feeling of not mattering when she said, "I was just the sister of the kid who had cancer;" and Amelia thought that it was important "[T]o have assurance that people still like love you, and they care about you, and that like, that you matter just as much."

In terms of the *need for acknowledgment*, Emily spoke specifically about needing acknowledgement from her parents who were occupied and preoccupied with taking care of her sick-sibling, "I just needed to know that I was still valid." Elizabeth, on the other hand, spoke specifically about wanting to be acknowledged by other people when they enquired about her younger sister Kate's health status:

I think, like, I started to get really frustrated that people never called to ask about me. People called to ask about Kate. It didn't matter that I knew she was sick and of course people would call to ask for her, but I am still a person. And at the time it just felt like it didn't matter that there was an Elizabeth or Adam, it was just about Kate.

Not being acknowledged, rather feeling invisible or sometimes outright ignored, was experienced across multiple situations and from multiple sources. This is exemplified in an extract from Amelia's narrative describing an experience on her brother's Make-a-Wish trip to Disneyland. Amelia was standing between her brother and her older sister watching the parade in Disneyland, her brother was wearing a Make-a-Wish button that let people know he was there under special circumstances and her older sister was in a wheelchair due to non-cancer-related health concerns:

We were watching the parade and we were on the sides and they, Chip and Dale, came up and they—they—they gave a hug to my brother, and they gave a hug to my sister, and they walked right by me. [Tears up] And its stupid to cry about it now, but I was like 12 right? And I remember like, all the Disney characters and all the staff they really ignored me. Like 'cause my sister was obviously in her chair—and I remember Cinderella—that bitch—she kind of pushed me out of the way and put her arm around my sister for a photo and I was like—you can see in the picture I was like crying....Like if Chip and Dale had just also included me I would have been fine right? Like people just need to realize that like the sibling is going through as much as the other, as the siblings right?

Regarding *the need for attention* (from parents or others) in the form of deliberate and effortful attention-giving, or the setting aside of attentive time just for them through, for

example, open acts of acknowledgement such as birthday gift giving and ongoing involvement in *their* lives, siblings perceived this to mean that “I matter [and that] I am not a burden.” Diana described why this type of deliberate and effortful attention was so important in helping her to feel acknowledged and that she mattered, and that she was not a burden:

Because the time has been made, you're not a burden on their day, a burden on their life, in general. Because they have set that time, and it is set-aside with that idea in mind, so you don't have to take the responsibility for taking their time because they gave it to you.

Simmi said:

Every kid needs to be cared for and deserves their parents' attention. If anything—there were basketball games, and I was very sporty growing up. So basketball, field hockey, volleyball, I had games and I remember—like not once did my parents come to any of my games.

Amelia shared a “wish” she made in the hopes of gaining attention:

So like, I remember— and this is horrible— I remember at one time wishing that I got sick, because I wanted attention. And that made me feel guilty because you shouldn't be wishing that, because your siblings didn't want that to happen.

Overall, this first thematic finding of well-siblings' need for acknowledgment and attention was neatly summarized by the advice Amelia would like to give to health professionals, parents, and any other people regarding the well-sibling's experience.:

Almost just like treat them [the well-siblings] not as someone with a sibling who is going through something. Treat them as someone who is going through something.

The theme the *need for acknowledgement and attention* was initially supported by 6 participants who confirmed the need for acknowledgement and all 7 confirmed the need for attention. Upon

member checking, both the need for acknowledgment and attention had a 100% endorsement rate.

Theme 2: The Need for Honest and Open Family Communication

All 7 participants expressed a need for more honest and open communication with their parents, their diagnosed sibling, and their other well-sibling(s). The siblings shared a need for family communication beginning from the time of diagnosis. This need in general was to talk more as a family collectively as well as with one another, during the time of crisis. It asks parents and children to communicate with one another about their thoughts and feelings about the diagnosis and other life events during this time. The need for communication appeared as a remembered need for conversation and connection, and for some it presented as what sounded like an invitation and permission to communicate about the crisis.

Jocelyn discussed how she and her brother did not talk and still do not talk about his cancer. She recalled the experience of watching other children her brother's age dying from similar cancers as his. She wondered if she had talked to her brother about the emotions she was feeling about his illness and had the conversations, that maybe it would have given him permission to share his fears. When I asked her what she needed during that experience she said:

Probably talking to him about it. We never really did. Didn't really want to bring it up with him? I didn't know how much he wanted to talk about it. Ummm and I never really talked about it with anyone either. Ummmm, yah no, I never really did. So, probably should have done both of that [laughter] I definitely should have talked to him. I still haven't. Like I don't know how he feels about it.

Diana expressed a need for conversation both in the past and in the present regarding her sibling's diagnosis:

Because now that I've thought about it, I don't think my dad and I have ever sat down and talked about Anne's experience or that timeframe. Mom and I definitely didn't. It was spoken of, but not really discussed.

All 7 participants expressed a need for more family communication, most particularly honest and open family communication, with their parents, diagnosed sibling, and their other well-sibling(s) during their interviews. This need was confirmed again by all 7 participants during member checking.

Theme 3: The Need for Inclusion in the Family during Treatment

Six of the 7 participants spoke about needing to be with rather than physically separated from their family—whether by parental decision or the child's choice—during their siblings' treatments. During times of treatment, some participants reported feeling like outsiders to what felt like a reorganized family unit or “little team” (Emily) that they were not a part of, and which they were “orbiting around” (Diana). This was experienced as unfair, or psychologically isolating and emotionally confusing. The need for physical inclusion in the family unit extended to being included through information about their siblings' diagnosis and treatments, and what both meant (i.e., their implications) for both the sick-sibling and for the well-sibling them self.

The more I think about it, the more jealous and frustrated, sad, alone, and like left out I felt... I remember being so annoyed that we were being sent off, because it didn't seem fair that because of what Kate was going through that we had to go away as her siblings... I thought about this a lot over the years and I hate to say it, but I remember I think that it's like, it was a sadness that something was happening to my sister but there was no inclusion of Adam and I that seemed to be happening. (Elizabeth)

Emily's parents had given her the option to stay home while her older sister received treatment available only in the close-by but larger city of Vancouver. She shared what it was like from her vantage point:

I think it felt like they were a little team I guess, and I wasn't part of it ... I mean I had not only like been left in that they were focusing their attention on Erin, but I had been like actually physically been left. Umm, ya and while it was like fun and I was with my uncle and we did all these fun things and I could eat whatever I wanted and stay up as late as I wanted. Like, that feeling that she needs them so they're with her and not with me. I really do think that would have been mitigated a lot if they had just moved us all to Vancouver, and they were trying to do their best, they're not pulling me out of school but, ya, I don't think that a kid can see it that way... they were trying to keep things normal for me, but I wanted to be included ... I just, like, I just needed to be part of it.

In contrast to the other 6 participants, Jocelyn spoke about how she was included during her brother's treatments: physically by going with her family to Vancouver and staying together in the *Ronald McDonald house*, and, informatively, by her parents who kept her honestly informed about her brother's treatment:

I was never told anything to pull the wool over my eyes or anything like that. I just kind-of had it explained to me like "Ya, he had leukemia and ya it's life threatening." But I was always told like in the beginning what treatments he was getting and what they were doing and with every new treatment I knew what was going on and how they were giving it to him and what side effects it was going to have.

Six of the 7 participants spoke about needing to be physically and psychologically

included in their family unit during their siblings' treatments. Upon member checking, all 7 participants endorsed this theme.

Theme 4: The Need to Know that it is Normal to have Difficult Emotions and Uncomfortable Thoughts

All 7 participants expressed feeling difficult emotions (e.g., anger, jealousy, hatred, confusion, and frustration) and thinking uncomfortable thoughts (e.g., thinking the sick-sibling was ruining the family, wishing they were sick too so they could get attention) when their siblings were sick. Participants said that they needed to know that these feelings and thoughts were normal and that they were allowed to have them. The outfall from not knowing that these kinds of thoughts and emotions were normal caused the siblings to feel guilty for both their feelings and thoughts.

It sucked. I don't know. You just feel really lost and confused and you have so many different emotions of like, confusion, and jealousy and more confusion ... it makes you confused because you get jealous, but then you're like, "I'm healthy why should I be jealous?" (Amelia)

I remember feeling [pause] guilty that I didn't cry. People always would—well everyone around me was crying—family and friends and friends and their parents. And I was just always like, "He is going to be fine. Like what's the big deal here, he's gonna be fine".... Like I never felt like ... it was more so, like my later teenage years that it kinda hit me, like the severity of it and what he really went through. (Jocelyn)

I would never want to say that to anyone who would believe that I actually hated my sister. Or how dare I be the bitch that's saying anything mean to my sister who just went through this. So you feel like a total bitch and like what the fuck is wrong with me for even feeling this way towards this person that could have died? That is lucky to be here. You know? Like how dare I do that? So I didn't give myself permission. Those kind of things, so something about that, like venting that may not be real, but letting out the emotion, words and not having to feel guilty about it...I think there was just a huge amount of guilt to have anything against her, or for her to be wrong. (Bree)

Theme 4, *The Need to Know that it is Normal to have Difficult Emotions and Uncomfortable Thoughts*, was succinctly described by Emily, who, during her interview, said:

I think that kids, siblings, or I needed to know that it was ok to have those feelings, because it really was. It was normal to have those feelings, and it didn't make me a bad person, but you can't possibly know how to control these big feelings when you're a kid. There's these huge things going on, and you only have so much body space for all these emotions right? Umm, so, maybe the guilt wins over everything and then you end up feeling mostly guilty.

Theme 4 was described by all 7 participants during the interviews, and endorsed by all 7 participants in member checking. The need for support available specifically and exclusively for well-siblings became evident in my reading of the data, sufficient enough (5 of 7 participants spoke explicitly about this need) to signal and warrant the subtheme, *The need for support exclusively for well-siblings*.

Specific and suitable support exclusively for well-siblings was described in the forms of programs and peer-support for well-siblings, and also in the form of counselling. The programs and counselling were seen as a way of supporting the siblings through their difficult emotions and uncomfortable thoughts. Programs were described as a place where siblings could have the venue to talk with other well-siblings who had a sibling diagnosed with and being treated for cancer either presently or in the past. Fellow siblings were most likely to understand the cancer experience from the sibling perspective, including the experience of uncomfortable, difficult, and confusing feelings and thoughts. In this way, siblings could serve as peer-supports (where “peer” refers specifically to other siblings of children and youth with cancer) to provide one another with relieving and normalizing emotional support.

If I ever told them how I felt, I know they (siblings who also had a sibling go through cancer) would understand because they went through the same thing I did, and they felt the very same thing. No one is perfect. You're going to hate your sibling, you're going to love them, but you're going to hate them.... [w]hereas if I told someone else, like even my boyfriend like, "Yah I hated my brother, but I love him. Does that make sense?" Right? Like it's not something that's going to make sense to people who don't understand.

(Simmi)

'Cuz I don't remember having an opportunity to have a support group with other kids and I think that would have been really helpful. Like it was just Adam [well brother] and I who were going through this. I never knew of anyone else until I went to Camp Goodtimes and I was a counsellor, where other people had siblings or were there as campers with siblings. And I think there was some sort of sibling support group and

maybe we were just too far away to go to it in North Van where Children's hospital is. I don't know, but I feel like that would have been really good, I feel like I would have been receptive to it. (Elizabeth)

As a teen, Diana and her family had been invited to attend *Camp Goodtimes*. Diana recalls her reaction to this invitation:

I thought it was really interesting that I, as a sibling, would have been invited to the same camp. So to a camp where it's all about cancer, which is great for the kids with cancer, 'cause then they're sharing that with other kids who have cancer. But I don't know if that would help the siblings, I don't know because I didn't experience it ... it was kinda like being invited to a club that you didn't have membership too ... Perhaps siblings need to get together and have more opportunities to be supported.

Data extracted from Amelia's transcript endorses Diana's concern that well-siblings might feel like outsiders of "a club" and the suggestion for support programs for well-siblings exclusively.

Amelia, who did attend *Camp Goodtimes* as a sibling, reported:

I remember being in a cabin it was, umm, all of them were cancer patients except for me and one other girl. I remember we both felt kind of weird because umm, because umm, they were all talking about their cancer stories. Oh I am just remembering, I am remembering this more now. But I remember them talking about their cancer stories and we kind of felt left out and then they were kind of like giving the vibe of, "Oh you guys don't know right, blah blah blah." And we were like, "Oh you know it is hard for us." And they were like, "Oh it's not the same, it's way harder for us." And it was like, "Ok, like, you can't say that right?" And that really pissed me off.

Help was recognized in the way siblings shared a need to be listened to by a helping professional, someone who could offer support without judgment, for example:

It was nice because that person was just like a complete stranger and no bias or connection. Like they were willing to hear your side of things, because no one asks about the sibling that much. (Jocelyn)

In sum, during their interviews, all 7 participants expressed having had and feeling difficult and uncomfortable emotions and thoughts when their siblings were sick. All 7 participants endorsed this theme in member checking. In their interviews, 5 participants spoke to the need for specific and suitable sibling support programs exclusively for well-siblings. Upon member checking, 6 participants supported the need for specific supports for well-siblings, and Emily wrote on her feedback form: “I think the subtheme of the need for support exclusively for well-sibling is an important one.”

Theme 5: The Need for Instrumental Support

Instrumental support helps well-siblings (and their families) bridge the world they know with the new cancer world. All 7 participants described needing the instrumental, practical, and social support from sensitive, understanding, thoughtful, and advocating others. For example, the support could look like making efforts to keep well-siblings involved in sporting activities; providing school work for siblings to complete while they are away with their family for their sick-sibling’s cancer treatments; or support to facilitate conversations, from the time of diagnosis through the sick-sibling’s treatment, between well-siblings and their parents and within the family as a unit, and with friends and broader community members (e.g., the well-sibling’s classmates). This support was described as coming from three sources, each of which was mostly consistent across participants. For this reason, I abstracted out these sources as 3 subthemes of

the need for instrumental support: (i) support from family and friends; (ii) support from school teachers and other adults involved in their lives at the time (e.g., coaches); and (iii) family-level support from helping service-workers and professionals for the family as a unit. These 3 subthemes are reflected in the following verbatim quotes:

Subtheme (i). The need for support from family and friends.

I guess I just wouldn't have spent so much time alone probably. I mean if I wasn't in school then I was at home alone, and so someone probably to take me out of the situation so that I, you know, I wasn't orbiting around the situation. I could orbit around something else. I could be part of something else. (Diana)

The good thing was that I had a great support system in my brother [younger well-sibling, Adam] at the time and we had wonderful family members surrounding us and we were really lucky. (Elizabeth)

It was just 100% all the people around us, my grandparents were so good. My family is really close, my cousins, my aunts and uncles; it's a huge family. Umm and that 100% made it ok because I don't know how much my friends could have helped me because how could they really understand? Most people just kinda feel awkward when it comes to that kind of stuff, 'cause they don't know what to say. But with family we're all so close and comfortable so they made it for us. (Jocelyn)

Subtheme (ii). The need for support from schoolteachers and other adults.

I went to a really small elementary school it was a private school and so I was in Grade 7 and when I came back from that initial Vancouver trip ummm they brought my whole

class to the library and the public health nurse came in and talked about cancer with everyone one and was like, "This is what it is, Joce's brother has." Ummm and she was just like, "Does anyone have questions? This is what will be happening." And they did that for his class too, even though they were so young. But ya, they just told everyone. I think to avoid me having to explain it to everyone. So everyone knew. (Jocelyn)

While Jocelyn felt supported by how her school handled it, Simmi felt angry and embarrassed. She told of how she returned to school after being away to find out that her teacher had told her whole class what was going on:

So when I got back after the weekend, everything changed. So all the kids that were being mean to me or didn't understand me, were being really nice, and I didn't understand why, until my best friend Robert told me she (the teacher) told everyone. I was so angry, I was like, "Why, why?" and then the whole school found out, so wherever I went it was like, I couldn't escape their looks, and then they put me on the spot all the time in class for show and tell "oh how's your brother doing?"

Bree talked about how she felt unsupported at school and what she needed:

[I needed] like even teacher's encouragement too, maybe?... Yea, like I played a lot of sports, so if somebody was just like, "Okay, I know you're going through a hard time, but can you come to practice or do you need a ride to practice?" Like setting something up, like an extra support like that maybe was what I would have needed at that time.

In contrast, Jocelyn recalled how her volleyball coach had supported her ongoing involvement on the team while she was in Vancouver for her brother's treatments:

I played volleyball the whole time and soccer, but volleyball was like my big thing. I absolutely love it and I still play it in university.... Maybe I would miss a couple (of

practices)—not games, cuz I woulda chosen to play at the games over going to Vancouver. I loved volleyball. Maybe I would miss some practices, but if I ever said to my coach, “Like this is why and where I’m going, he would be like ‘Oh, go!’” He would never say anything, he was kinda like that for e-v-e-r-y-t-h-i-n-g. Who knows how other people felt about that, but I would always get a free pass. Everyone always understood.

Subtheme (iii). The need for family-level support from helping service-workers and professionals. Diana, for example, wished that there had been an outside source of professional help to facilitate conversations between her and her parents from the time of her sister Anne’s diagnosis through her treatment:

Thinking about it now, facilitated conversation probably was what we (the family) needed ... We would have needed outside help to help us mediate that conversation [talking about Anne’s cancer diagnosis]. We still would need outside help to help us mediate that conversation ... as a family unit we probably could have used support.

All 7 participants spoke about needing the instrumental, practical, and social support of sensitive, understanding, thoughtful, and advocating others in their interviews with me. All 7 participants once again endorsed this need through member checking.

Theme 6: The Need to Just be a Kid

Five participants reported being given inappropriate responsibilities and sometimes feeling burdened by either their perceived need to take care of things and people (including their parents’ feelings), or by clearly stated expectations to take on adult responsibilities due to the crisis within their family. There appeared to be a fine balance between the need for inclusion and information with the need to just be kid. To be a kid is to be free from overbearing adult responsibilities, including not having to make decisions that are too big for a child to make.

I tend to look forward, look backwards, look all around. So, so, it's hard to let go of those responsibilities but if someone could have made that happen that would have been really nice. To have a moment where it wasn't about trying to fix things or trying to support things, (where) it was just about the moment... I think just having that time with someone where I wasn't responsible for them. So I wasn't responsible for them, and I wasn't responsible for anybody else. (Diana)

It was always, "Well Elizabeth can take care of herself." But I don't think at that point I actually could, so then it was, "Elizabeth can you take care of Adam while we take Kate to the hospital? Can you prepare and heat up the lasagne?" (Elizabeth)

Like I think it—for my mother for example I wish she would—I wish she would've gotten (emotional) help. Like I didn't want to be her friend— not that I was— we didn't have that thing going on. But, parents are supposed to be the parents too, for the kids. They wanna cry and they want their parents to hold them. (Bree)

Umm, my parents asked me at some point in that first week if I wanted to—so I had just started at this new school, and I had moved to Mayne and umm, they asked me at some point if I wanted to be in Vancouver with them, or if I wanted to be on Mayne, and they, for some stupid reason, let a 10- year-old make that decision. So I decided to be on Mayne... I don't think that decision ever should have been put on a 10-year-old, because like it has caused a pretty big divide in our family ... I just wanted to be a 10-year-old. (Emily)

The theme of *the need to just be a kid* was represented by 5 participants in the interview data, but after member checking it had a 100% endorsement rate.

Theme 7: The Need for Humour, Laughter, and Light-heartedness

All 7 participants spoke about moments of humour, laughter, light-heartedness, and even silliness, which often included or involved their sick-sibling, and how these had been meaningful and important to them during the cancer experience. These moments and times had been enough to bring “a lightness” and “relief” to this difficult time. They created lasting memories that continued to be comforting and positive to bring to mind and talk about in the present.

Kate had this doctor balloon that a family friend of ours gave her—it was one of those big foil balloons that they fill with helium and have a happy face and had some sort of stethoscope that hung off of it and it had a smile on it and Kate got it in the hospital and my parents refilled it for her for months. And it was this thing that—it was so funny to all of us because it brought this, to like put it into adult words, it brought this lightness, to this situation. This like humorous yellow balloon with a stethoscope doctor face, and it would like float around the house and Kate would carry it around the house. Those moments where you’re like, everything is so serious and so stark, but in comes this five-year-old child with a yellow balloon that has a doctor on it and you can’t help but laugh and make light of everything [laughing]. (Elizabeth)

Umm actually I thought of something for like how me and him would joke and stuff, and how he would always joke and stuff. [Laughing] When he first started his treatment—and this is just how our family was—we were at Ronald McDonald house and his hair was starting to thin and [laughter] we like, we’re in this room where it was a double bed

below and the bunk on top, like a single. He was up top, and I think I was on the floor maybe and my mom was in the bottom bed and she was like reading a book and we were trying to sleep. So she had just a little light on her and she found like—or just keep seeing like shadows and stuff and didn't really think anything of it. Then she started being like, "Okay what the heck is this? I keep seeing things around me." Then she's like, "Alex are you awake?" like above her. Then he started giggling, and she's like, "Oh my god!" and she looked around herself and he was pulling his hair out and dropping it on to her [laughter] and we all just started laughing so hard. Umm and she's like, "Oh my god, you are such a brat!" and he was just pulling it all out and dropping it on her. He just thought it was the funniest thing in the world. Umm like, we just, I dunno, we took everything so lightly. That was the funniest thing ever. Like he didn't want to shave his head, he just let it umm, he just thought it was hilarious to pull out his hair... Thinking of that story makes me so happy that he was like giggling at that. But that's how we got through it. We never would have shared that, umm but in our family like we made the best of it. (Jocelyn)

I think that the thing that is missing is the positive bits. And those are the things that I don't really remember. Umm, and uhh, the bits where, like she would come home and she wouldn't be that bad that week, and we would be good ... it's nice to remember the positives. (Emily)

All 7 participants originally endorsed this theme, and all 7 also confirmed it upon member checking.

Chapter Summary

In this chapter I presented the findings from my thematic analysis of my participants' narrative interviews. Within the transcribed data, I found 7 themes that highlighted the needs of well-siblings when their brother or sister was diagnosed with and treated for cancer: (a) The Need for Acknowledgement and Attention; (b) The Need for Honest and Open Family Communication; (c) The Need for Inclusion in the Family during Treatment; (d) The Need to Know that it is Normal to have Difficult Emotions and Uncomfortable Thoughts; (e) The Need for Instrumental Support; (f) The Need to Just be a Kid; and (g) The Need for Humour, Laughter and Light-heartedness. Two themes comprised subthemes: *The Need to Know that it is Normal to have Difficult Emotions and Uncomfortable Thoughts* subsumed the subtheme, *The need for support exclusively for well-siblings*; and *The Need for Instrumental Support* subsumed 3 subthemes, (i) *The need for support from family and friends*; (ii) *The need for support from schoolteachers and other adults*; and (iii) *The need for family-level support from helping service-workers and professionals*. In the next chapter I will provide an examination of these findings in comparison to the existing literature as well as suggest what I believe my findings mean for theory, future research, counselling psychology practice, other helping professionals and service workers, community members and for families and well-siblings themselves.

Chapter 4

Discussion and Conclusion

For the past 50 years, the psychological, physical, and emotional impacts of cancer on the child diagnosed with cancer and their parents are vantages that have been explored extensively (Wilkins & Woodgate, 2005). However, as Jocelyn, a participant in this study said, “*No one asks about the sibling that much.*” In this final chapter, I discuss the findings of my study, which, to the best of my knowledge, is one of the first to specifically ask adult siblings retrospectively about their cancer experience as an adolescent. I present these findings as they relate to the current literature and how they support and extend what we already know regarding the experience of well-siblings. I also include auxiliary findings and discuss the strengths and limitations of my study. Next, I discuss the study’s implications generally and, more specifically, for the field of counselling psychology. Lastly I provide suggestions for future research and a conclusion.

Summary and Discussion of Findings

Seven themes relating to adolescent well-sibling needs were identified from the narrative interview data: (a) The Need for Acknowledgement and Attention; (b) The Need for Honest and Open Family Communication; (c) The Need for Inclusion in the Family during Treatment; (d) The Need to Know that it is Normal to have Difficult Emotions and Uncomfortable Thoughts; (e) The Need for Instrumental Support; (f) The Need to Just Be a Kid; and (g) The Need for Humour, Laughter and Light-heartedness. Theme 4, *The Need to Know that it is Normal to have Difficult Emotions and Uncomfortable Thoughts* subsumed the subtheme, *The need for support exclusively for well-siblings*; and 3 subthemes were subsumed under Theme 5, *The Need for Instrumental Support*, namely: (i) *The need for support from family and friends*; (ii) *The need for*

support from schoolteachers and other adults; and (iii) The need for family-level support from helping service workers and professionals.

THEME 1: The Need for Acknowledgement and Attention

Participants articulated the independent but not mutually exclusive needs for acknowledgment and attention, particularly from “*my parents*” (Elizabeth), but also from others—extended family members, teachers, friends, professionals, and members of their community. Participants spoke about feeling like a burden and as if they were peripheral, invisible, unimportant, incidental, or like, as Emily said, “*just the sister of the kid who had cancer.*” When their sibling was diagnosed with cancer they remembered needing and, in many cases, wanting, to be acknowledged, respected, seen for who they were and for how they were doing, and to be reassured they “*matter[ed] just as much*” (Amelia). To acknowledge means to openly accept, admit, recognize, or affirm the existence of a fact (Merriam-Webster, 2014); in this case, the existence of the well-sibling and that they have needs (too). By definition, acknowledgment (or its perceived absence) is communicated either directly through spoken words or indirectly through attention and other forms of nonverbal communication. The giving or paying of attention to another is a gesture of recognition that communicates the attention-giver’s interest in, or awareness, mindfulness, noticing (Merriam-Webster, 2014), or “seeing” of another. In other words, the giving or paying of attention communicates the attention-giver’s awareness and acknowledgment of the other.

Theme 1 corresponds directly with one of the four needs identified by oncology nurses (*Getting attention*) reported in the O’Shea group’s (2012) study. My finding of well-siblings’ need for acknowledgement and attention is also consistent with needs identified by Wilkins and Woodgate (2005) and Patterson’s group (2014). The need for acknowledgment and attention is

arguably subsumed under Wilkins and Woodgate's first theme, labeled *changing lives*. Specifically, the need for acknowledgment and attention is identifiable under the subtheme of *losses* in which siblings (across multiple studies reviewed by Wilkins and Woodgate) experienced a loss of time spent with their parents. In the Patterson et al. (2014) needs inventory, *Sibling Cancer Need Instrument* (SCNI), there are several items comprising the need domain *understanding from my family* that speak to well-siblings' need for acknowledgment and attention. These items are: "For my family to acknowledge that this is happening to me too"; "To be treated as a member of the family rather than as a 'bystander'"; "To know my parent/s haven't forgotten about me"; "To be able to spend time with my parent/s—just me and them"; "To be noticed and have some of the attention from my family members"; and "To feel that I am just as important and valued as my sibling with cancer" (p. 657). Other literature has also indicated the well-sibling's need for both acknowledgement and attention (DiGallo, 2003; Patterson et al., 2011; Murray, 1998; Woodgate, 2006).

I additionally suggest that my finding of well-siblings' need for acknowledgement and attention overarches and includes the needs for *support to maintain own interests and activities* identified by Wilkins and Woodgate (2005), and with *wanting a normal routine* identified by O'Shea et al. (2012). In my study, Elizabeth spoke tacitly to her need for acknowledgment and attention when she shared about her experience of missing and wanting her mother's involvement in her dancing, soccer, Girl Guide's group, and birthday party. When her birthday was cancelled due to her sister's diagnosis she had to celebrate with her grandparents:

They took us to McDonalds for my birthday and they thought they were doing something really great, and I remember everyone had tons of fun but me. I was, so angry that they had taken me to McDonalds. It's funny, I have no idea why? They had gotten me a nice

ice cream cake. But my mom had always done such a good job at hosting birthday parties and she was so amazing that I had probably had something spectacular planned that year that was like being whipped away.

Therefore, it was particularly touching for Elizabeth when she returned home to find her friends had planned a surprise makeover birthday party for her, that was, in her words, “*pretty special.*” This example of acknowledgment (by her friends) illustrates how “*even small things*” as Simmi said, can make a big difference.

While I did not share a quote from Bree’s birthday story in Chapter 3, Bree was 1 of 3 participants who spoke about the frustration they experienced around their birthday being altered because of their siblings’ illnesses. Bree shared memories of feeling angry that her sister Lily would also receive gifts on her (Bree’s) birthday. She made a comment similar to that of Amelia and Elizabeth in her exasperated attempts for attention, “*What? Do I have to get cancer so I can get gifts on everybody’s birthdays now?*” Bree, like Elizabeth, also shared how this need for special attention and frustration around birthdays was heard by others: “*One time, my mom—it was Lily’s birthday—and she gave me a gift on the side, so something like that she heard me, and did something sweet for me, so that was nice.*” In their experience of feeling unimportant, Elizabeth and Bree illustrate the positive inverse of what it is like to receive attention and acknowledgement. Of course, cancer and its treatment does not decide when it will arrive; whether it be birthdays, Christmas, Easter (Woodgate, 2006), Hanukkah, family vacation, or at any other times in the natural course of celebrations and daily activities of family’s lives. However, given the North American makeup of my sample and that birthdays are of particular significance in North American culture and are celebrated as a way of honouring someone in a special way, it is possible that my participants would have relied upon their birthday to be the

one day of the year when it was all about them. In other words, I am not sure that siblings in cultures where birthdays do not carry the same significance, would interpret the downplaying of their birthday to mean they were less important and less deserving of attention than a sick-sibling.

Other than the celebration of birthdays, participants in my study wanted acknowledgment and attention in the form of physical affection, time spent with them, and encouragement and (re)assurance of interest in their activities, personal interests, and attendance at school and extracurricular activities and performances. Elizabeth noted her mother's unavailability to attend her dancing, soccer, and Girl Guide's group (Elizabeth's mother had been a leader of her Girl Guide group prior to her sister's illness):

I feel like that was really hard on me, and I was envious of my friend's parents who would come to their events. My parents had always been so good about coming to my games too on Sundays and my dad kept coming but my mom was—like my mom always had to be at home with Kate.

And, Bree, for example, told me:

I feel like I fucked up high school [tears up]. Like I barely graduated and I think if my mother had the strength to give a fuck about grades and things like that, and I don't think it was that important to our family. But I do. It brings me sadness, and I was really good at sports. That was what I was really good at, and I just started drinking and partying and it was just ok, and just—I never got in trouble. Like I would be black out drunk and driving home, but nobody really said anything. So there, I think, I wanted somebody to ask me, "How are you doing?" but nobody did.

In contrast, Jocelyn shared how her family supported her to continue in her love of volleyball, even when her brother was sick. The need to have their own interests and continued involvement in activities supported and encouraged through attention giving was common across my participants and is a need that previous literature has explicitly addressed (e.g., Barrera et al., 2004; O'Shea et al., 2012; Patterson et al., 2014; Wilkins & Woodgate, 2005).

Participants in my study also provided stories of repeatedly being asked how their sick-sibling was but not about how they were, for example answering the family telephone and being asked only about their sick-sibling. Murray (1998), and Prchal and Landolt (2012), noted that well-siblings reported having to continually answer the question "How is your sibling?" Emily experienced this as a distilling of her identity to that of [being] "*just the sister of the kid who had cancer.*" Being considered for who they are in the cancer equation allows well-siblings to maintain their own identity beyond being seen only as the sibling of a child living with cancer, wondering "where do I fit in?" (DiGallo, 2003), or "what about me?" (Murray, 1998; Prchal & Landolt, 2012). In keeping with this, Wilkins and Woodgate (2005) also found evidence for the "loss of a sense of self" in well-siblings, and reported this as an aspect of their theme labeled *changing lives*. Patterson et al. (2014) captured this need for acknowledgement of personhood within their need-domain for *understanding from my family*. I suggest that one way that well-siblings receive understanding from their family, is in the form of acknowledgement and attention. In other words, that Patterson et al.'s need domain for *understanding from my family* is, at least in part, satisfied by the more basic level need for acknowledgment and attention.

The need for attention was so strong for some participants in my study that they went to great lengths to call out for attention. You will recall Amelia, and how she wished she was sick so she could get the same attention as her sick-sibling received. Yet another example is the story

Elizabeth told about an April Fool's joke, which she played on her Grade 5 classmates in the hopes of gaining their attention:

It was April Fool's Day and I thought I was being so funny and I was like "Kate's cancer has come back" and everyone was like "Oh my god, I can't believe that has happened. I'm so sorry, are you ok?" And I was revelling—this is ridiculous—I was revelling in people paying attention to me and it being about Kate. And I was like, "Oh, it's April Fool's!" and everyone was so angry with me, and I think I was in Grade 5 class, and deservedly so, that is a ridiculous April Fool's joke.

Previous literature (Koch, 1989; Murray, 1998; O'Shea et al., 2012) affirmed how very normal this type of attention seeking behaviour is in well-siblings who are in need of attention. As the 14-year-old sibling in Murray's study illustrated when she said: "I often thought if I got sick, maybe I too would receive presents and sympathy" (p. 222). It was also interesting to hear how, in our interviews, both Amelia and Elizabeth felt embarrassed and shameful in reporting their normative childhood responses and behaviours. Later during the member-checking process, both participants reported a sense of relief after reading that they were not the only ones who had thought or behaved in the attention-seeking ways that they had. Another example of a cry for attention was the behaviour of Bree who shared how she coped with her sadness (and, I suggest, with her implicit need for acknowledgment and attention) by engaging in risky drinking behaviour. She recalled a memory of driving home drunk one night and wondering if anyone was going to pay attention by saying something about her reckless behaviour, in this way recognizing her suffering, but nobody did.

Attention (or lack thereof) provided in ways such as these, seemed to serve well-siblings' need for acknowledgment. Emily reported that as a 10-year-old she had understood that her sister

was sick and needed her parent's extra care and attention, but, that despite this understanding, she still experienced a need to be recognized: "*I just needed to know that I was still valid.*" Awareness of the reality of why things were the way they were yet still feeling hard done by, is a common experience in well-siblings (Bendor, 1990; Wilkins & Woodgate, 2005). This need to matter—"to know that I [am] still valid"—best aligns with Maslow's (1943) hierarchical need for *love and belonging*. The need for love and belonging is described as a reciprocal need for connection, affection, affiliation, and love from another person in a relationship or group, and that is based on the giving and receiving of these types of attention (Glasser, 1998, p. 33; Maslow, 1943, p.381). In other words, Glasser and Maslow agreed that connection, affection, affiliation, and love from another person are forms of attention. Glasser (1998), went on to assert the need for love and belonging—in other words, the need for relatedness—as the most important need because all other general needs are satisfied through and in relationship (p. 43). The need for relatedness proposed by Ryan and Deci (2000) subsumes the need for love and belonging.

By acknowledging a well-sibling and asking them, "How are *you* doing in all of this?" they are given a message that affirms their place in the family. It also acknowledges that they are a part of the (family's) cancer experience, rather than, as Patterson et al. (2014) said, just a "bystander," or feeling like outsiders "*orbiting around*" (Diana) a "*little team*" (Emily). Further, well-siblings need to be given specific attention towards their own interests and life goals, and that effortful attention or lack thereof, according to my participants, affirmed or disconfirmed that they were "valid." The need for having time spent with them is what siblings in previous studies have also cried out for (Woodgate, 2006). One reason why this is important to well-siblings was provided by my participant Diana, who was articulate in explaining how she

believed she could have had her needs met by friends and family members deliberately setting aside time for her. She said that this could have helped to mitigate her feelings of being a burden: “*Because the time has been made, you’re not a burden on their day, a burden on their life, in general.*”

I think Simmi and Elizabeth’s words provide the most succinct way for me to conclude my discussion of Theme 1, *The Need for Acknowledgment and Attention* as the first finding of my study. Specifically that sometimes, the need for acknowledgment and attention can be satisfied in the simplest and most human way—with a hug:

[I needed] someone just to hug or someone just to be there one day of the week, you know? I think I craved people’s attentions. (Simmi)

All we needed at that time was also to have a hug. We needed our parents to umm to be there for us. (Elizabeth)

THEME 2: The Need for Honest and Open Family Communication

The need for honest and open family communication took different forms within the 7 participant’s stories. Participants reflected that they wished they had spoken more candidly with their sick-sibling about the cancer, while others wished there had been more discussion about cancer with their family as a whole. Understanding the intricacies of the health system along with the fears and the unknowns also required patient and honest family communication. It is not surprising therefore that participants in my study reported feeling unsure of how, if, and when to talk about cancer. While some siblings said it was communication with their parents that they most desired, family communication was seen as a form of connection between well-siblings and their family members.

In Wilkins and Woodgate's (2005) summary of previous literature they identified and subsumed the need for family communication as one of the four needs under their third overarching theme, *Unmet Needs*. Wilkins and Woodgate defined family communication as the act of being able to discuss thoughts and feelings about the diagnosis, amongst other daily-life related matters, during this time. They also offered that communication during this time within the family and particularly between parents and well-siblings, was strained and seemed to break down during the cancer experience. This communication breakdown could result in what Patterson (2002) described as a time of crisis: "a period of significant disequilibrium and disorganization in a family" (p. 351). O'Shea et al. (2012) saw communication primarily as a form of communicating information (*Wanting to know*), and supported the need for parents to give siblings age-appropriate information. In the stories of my participants I, however, heard the need for information being more strongly connected to the need for inclusion during treatment. Specifically when siblings were given information they felt included in the treatment and care of their sick-sibling.

There were several items on Patterson et al.'s (2014) SCNI that aligned with how my participants spoke about their need for communication in their families. Under the domain of *dealing with emotions* was the need item: "to be able to express how I feel about my sibling's cancer without worrying about upsetting people"; and "to know how to talk to my family about how I am feeling" (p. 657). Under the domain of *my relationship with my sibling with cancer* were the need items: "to know how to talk to my sibling about how they are feeling"; and "to know how to talk to my sibling about how I am feeling" (p. 657). These items closely resemble what Jocelyn expressed when she said: "*I didn't know how much he wanted to talk about it*". One other item listed by Patterson's group that also spoke to the need for family communication, was

the need “to feel that I can openly talk with my family about my sibling’s cancer”; an item that Patterson et al. put under the need domain *understanding from my family*. From the items listed by Patterson’s 2014 group, it seems to me that the expression of emotions is predicated on the ability to communicate honestly and openly.

The need for honest and open communication is supported by Buchbinder et al. (2011) who pointed out that in order for well-siblings to express emotions, there needs to be some form of open communication in the family. My participants Elizabeth and Diana were united in their need to speak with their parents regarding their siblings’ cancer in an honest and open way during the time of the diagnosis and treatment. Elizabeth shared that she wished her parents had been able to sit her down and explain what was going on and what was going to happen. Diana reflected a curious observation of how she and her parents had never, to her recollection, discussed her sister’s cancer together. The need for honest and open communication is not limited to the relationship between well-sibling and parents. The participants in my study also requested open communication between the sick-sibling and well-sibling. Jocelyn said that her natural inkling was to not speak about her brother’s cancer around him so as to remain someone who was still “*normal*” with him. Yet, she said, she thought that if she had, it might have given her brother the opportunity to talk about what was “*going on under the surface*” for him, and also may have given her an opportunity to share her feelings. Jocelyn wondered if her brother was:

[s]ecretly really sad about it too [his cancer and friends who died from cancer] ... I didn’t know how much he wanted to talk about it. I never really talked about it with anyone either. Yah no, I never really did. So, probably should have done both of that [laughter] I definitely should have talked to him. I still haven’t. I don’t know how he feels about it [the cancer].

Interestingly, DiGallo (2003) found that well-siblings who reported healthy interfamilial communication had better relations with everyone in the family, and it seemed to increase everyone's ability to cope with the cancer diagnosis. Wilkins and Woodgate (2005) reported that previous qualitative research studies collectively demonstrate that communication between the well-sibling and their parents is a strong indicator of the well-sibling's ability to adjust to changes in their family's structure. But, figuring out *how* to talk honestly and openly about a life-threatening illness like cancer—which can be like learning a new language—and also *how much* honesty and openness to give and receive, often times requires support and help. An example will be helpful here. Bree (15-years-old at the time of her sister's illness) explained that her parents chose not to share the severity of her sister's illness with her. Instead, they gave her information about the types of treatments her sister would have and how those would help her. She recalled that there was a focus on the positive mindset that these treatments would work. Bree was aware that death was a possibility, but recalled that it was not until several years later that she learned how close that reality really was. Some readers might consider Bree to have been unduly shielded or protected (given that she was 15-years-old) from the honest severity of her sister's illness. From Bree's perspective (and the perspective that counts, in this case), she appreciated the amount of information she was given: just enough to be involved and informed, but not enough to be, as she expressed, "*scared.*"

On the *SuperSibs* website they offer a resource for parents called the "Parent Tool-kit" in which they offer guiding suggestions for how to speak to children at different ages about their sibling's cancer (SuperSibs, 2015). *SuperSibs* offers suggestions for facilitating a conversation with what they call "tweens and teens (11-18)", they suggest starting with the basics of the cancer and then elaborating to the degree that the well-sibling wants to hear and asks for. They

state some kids, “want a lot of information, some want to read about it themselves, and some want to know only what they need to know.” For example, I suggest a conversation might look like:

Well-sibling: “Is my sister going to get better?”

Parent: “What do you think? Do you think she’s going to get better?”

Well-sibling: “Some days yes, some days no. But, I know she has cancer.”

Parent: “What do you know about cancer?”

Parents (teachers, nurses, and other helping professionals), I think, are well advised to be child-lead. That is, to respond to children’s questions honestly and openly with large doses of collaborative and out-loud conversation-starters, “what-if” wondering, and titrated informational/educational opportunities.

At the same time, I think it is important to point out the findings by Brett and Davies (1988), who suggested that not talking at great length about the cancer in the initial stages of the diagnosis can actually be helpful, because it gets people through the crisis of the diagnosis. However, long-term avoidance of talking about the cancer can be detrimental (as cited by Wilkins & Woodgate, 2005). While Jocelyn did not report a detrimental effect from lack of communication with her brother, she did share a feeling of loss. She also expressed curiosity about how her brother did and does feel about his cancer. This brings to mind the well-siblings in Lehna’s (1998) and DiGallo’s (2003) studies. The well-sibling in Lehna’s study felt emotional about her sister’s illness, but did not want to cry in front of her sister because she wanted to appear strong in front of her. In DiGallo’s study, the now adult well-sibling wondered if her sick-sibling knew what it was like for her during her illness. DiGallo (2003) remarked that this well-sibling appeared to be “pre-occupied” with the communication that was left unexpressed

between well-sibling and sick-sibling. Taking the knowledge of Jocelyn in conjunction with previous literature, I suggest that it would be beneficial to encourage sick and well-siblings to talk to one another about the cancer experience.

In general the need for family communication speaks to Ryan and Deci's (2000) need for relatedness. Through relatedness and open communication well-siblings can gain a feeling of competence that they can handle the situation at hand and a sense of love and belonging; if I am communicated with I know that I matter and belong in this family (Glasser, 1998; Maslow, 1970). My participants highlighted their remembered need for family communication. This need and its importance is underlined by the words of Maslow (1970) who said, "secrecy, censorship, dishonesty, blocking of communication threaten *all* the basic needs" (p. 47) and by the conviction of Glasser (1998), who said, "the best way you can communicate that you love your children is always to be open to talking and listening" (p. 209).

Thus it can be inferred that the basic needs of the well-sibling (physiological, safety, love/belonging, esteem and self-actualization) can be attended to through honest and open communication in the family. According to Walker et al. (1992), open family communication in families with a child receiving a diagnosis of cancer is one of the "most important facilitative behaviors for patients, parents, and siblings" (as cited in Murray, 1998, p. 219). Therefore, it makes sense that participants highlighted this need, and that the need for communication involved, in the end, everyone in the family.

THEME 3: The Need for Inclusion in the Family during Treatment

Theme 3 represents well-siblings' need to be included in the family unit when their sick-sibling was receiving treatment. This was seen as being given pertinent and age-appropriate information regarding their sibling's treatment (including drugs, hospital stays, and the side-

effects) and by being able to help (e.g., by doing thoughtful, practical, or comforting things for their sick-sibling). Participants spoke about needing to be psychologically and physically with their family rather than feeling like outsiders “*orbiting around*” (Diana) what felt like a structurally reorganized family unit or “*little team*” (Emily) that they were not a part of. The need for inclusion in the family unit extended to being included through information giving about their siblings’ diagnosis and illness, and about the implications for both the sick-sibling and for the well-sibling. Not feeling included was experienced as unfair, psychologically isolating, and emotionally confusing.

Wilkins and Woodgate (2005) reported “the need for involvement in the care of the sick child” and “the need for information” under their third theme *Unmet Needs*. O’Shea et al. (2012) addressed these needs under *Wanting to help* and *Wanting to know*. Patterson et al. (2014) spoke to the need for inclusion under two domains. The first domain was: *my relationship with my sibling with cancer*, where the need-based items “to know ways of giving practical support to my sibling” and to “feel included in my sibling’s cancer experience” (p. 657) highlighted the well-sibling’s need for inclusion during treatment. The second domain was the need for *information about my sibling’s cancer*, and the items that articulated this need were: “to be informed about my sibling’s condition—good or bad” and “to be able to get information about my sibling’s type of cancer and its treatment in a way that I can understand” (p. 656).

Wilkins and Woodgate (2005) reported that siblings who remained included in the family during treatment felt more connected to their family and became a “legitimate part of the [cancer] process” (p. 315). They also suggested that when siblings were provided with information it helped them to adapt to the changes in their family structure. Information, according to Wilkins and Woodgate, could help siblings adjust to the vast amount of changes

happening in their family. Furthermore, Wilkins and Woodgate highlighted the value of parent-delivered information. (Participant Elizabeth, expressed the same thing in her interview when she said she needed to hear the information from her parents.) Patterson et al.'s (2014) SCNI includes an item that states that the well-sibling needs "to be spoken to by health care professionals in a way that I can understand" (p. 656). Participant Simmi, described how it was important to her for healthcare practitioners to deliver information in both an "empathic" and kid friendly nature. The nurses in the O'Shea et al. (2012) study shared the importance of both nurses and parents finding ways to give "roles" to the well-sibling in their sick-sibling's treatment. They described this as benefitting both siblings' relationships with one another, as well as supporting the well-sibling's understanding and feeling of inclusion in the cancer world. O'Shea et al. also suggested that active involvement in the care of a sick-sibling was particularly helpful for older siblings, predominantly adolescents.

Wilkin's and Woodgate's (2005) further reflected that feeling separate from parents and the sick-sibling tended to result in feelings of loneliness, rejection, and abandonment for the well-sibling. This point lends support and explanation to participant Emily, when she reported having felt "*left out and abandoned*" during her sibling's treatments. In DiGallo's (2003) study a well-sibling reported feeling helpless as to how to help their sick-sibling, which, on reflection, resulted in them feeling guilty. Bendor (1990) linked feelings of exclusion, which children inferred from the absence of their parents and sick-siblings, to low self-esteem. In the literature, self-esteem has been related to the need to be involved in the process of the sibling's care (Breyer et al., 1993; Cohen, 1999; Karampela, Hatira & Damigos, 2010; Lehna, 1998; O'Shea et al., 2012). Regarding the quality and quantity of information given to the well-sibling, age-appropriate and accurate information are important. Adolescent siblings' developmental

capacities, however, require a higher quality of information as compared to younger children (Murray, 1998; O'Shea et al., 2012; Wilkins & Woodgate, 2005). Being given information can also contribute to heightened empathy in well-siblings, which may influence psychological adjustment post diagnosis (Labay & Walco, 2004). According to Glasser (1998) giving teenagers age-appropriate responsibilities and information can increase trust, and as such the need for love and belonging is met (p. 213).

All 7 of the well-siblings in my study confirmed the need to be included in the family unit during their sick-siblings' treatments and wanting to help, even if "*I really couldn't do a whole lot, but I guess, whatever I could, I did*" (Simmi). Some of the participants said that they had felt included and "*welcomed*" (Jocelyn), by being given pertinent information from their parents and other health care professionals. That is, being given information was part of the inclusion process. While I see how the need for honest and open family communication (Theme 2) and the need for inclusion via information are interrelated, what I heard from my participants was the more discrete underlying need to feel included in the family during their sick-siblings' treatments. In the context of the need to feel included, family communication was (only) one way through which treatment and how-to-help information was gained. Inclusion for my participants meant that they continued to be recognized (i.e., legitimate, "*valid*") during treatments as members of the reorganized family unit. They experienced inclusion by being physically present for their siblings' treatments, by being kept informed, and by being able to help or to provide caring for their sibling. Exclusion from the family during their sibling's treatment experience, whether it was through physical absence or a void of information, brought up feelings of frustration, jealousy, and anger in their experience of feeling "*left out and abandoned*" (Emily).

Opportunities for well-siblings to gain understanding through information giving about the experience their sick-sibling is undergoing allows them to make sense of the treatments, as opposed to having to infer and imagine what is going on, which can lead to behavioural issues (O’Shea et al., 2012). For example, Amelia recalled seeing her brother’s *bravery beads*⁷ necklace from BC Children’s Hospital, which granted her information and thereby empathy for what he was going through. Seeing all the beads on his necklace shocked her and made her recognize that he was going through a lot. She said, “*I admire him a lot for that, because it’s amazing that he went through all of that.*” Jocelyn described how she enthusiastically engaged with information about her sibling’s cancer by compiling a binder of information about his treatments. For Jocelyn this was important to her journey, as she understood what the treatments were for and how they would affect her brother’s body. This, she reported, kept her focussed on the positive outcomes of her brother’s prognosis that he would—in her mind—absolutely get better. This focus, in turn, kept her feeling anchored (i.e., safe).

Simmi told stories of different ways she helped care for her brother, Harmen, while he was in the hospital by bringing him Slurpees and toys:

If I could do anything to make his day a little bit better I would... because I can’t be a doctor who administers medicine to him, and I can’t be my mom who offers him maternal love, nor am I my dad who offers him protection. I am just his sister. I really couldn’t do a whole lot, but I guess, whatever I could, I did.

It is important to recognize that inclusion through information giving, and support from parents and medical professionals to keep the well-sibling included, is no easy feat for families and medical professionals. As one nurse practitioner in O’Shea’s group (2012) said, “you have to

⁷*Bravery Beads* are beads given to the child with cancer to signify different steps and milestones along their treatment path. For example a white bead given for a chemotherapy treatment, and a glow in the dark bead for a radiation treatment.

constantly remind yourself to include that child, ask them if they have any questions, include them” (p.224).

Although it is ideal, being physically present with the family during treatments is not always possible for some well-siblings. For example, in British Columbia (where all my participants resided) as in many provinces, children’s hospitals and cancer treatment facilities are centralized and, therefore some families have to travel to receive treatment. Practical and important decisions then come to bear on families regarding well-siblings (e.g., school attendance, disruption or interruption of extracurricular interests, activities, and commitments). Also, for families who have to travel to access treatment, finding appropriate accommodation can be a stressor both emotionally and financially (Daniel et al., 2013). In reality, not all families will be able to financially make it possible for the well-sibling to be physically present. Four of my 7 participants saw their sick-siblings and parent/s travelling away from their home base for treatment.

When Emily discussed her experience of staying home, she told how she had felt left out and divided from the “*little team*” she felt her parents and sick-sibling had become. This division created a very real psychological impact on Emily, resulting in many years of feeling separate from her parents and sister. Kramer (1984) described this “*little team*” (to use Emily’s words) as a triad that forms among the mother, father, and sick child, which often results in feelings of loneliness in the well-sibling (as cited in Wilkins & Woodgate, 2005). (Adult) Emily said that her parents thought they were doing the right thing and had her best interest in mind when they gave her a choice to either accompany the family during treatments to Vancouver or to remain in her hometown with her uncle. Emily communicated that her parents have since apologized and admitted to her that they wish they had not given her that choice. Further, Emily also highlighted

the point that travel and staying connected can be stressful and a financial barrier for many families (unknowingly echoing the comments of Daniel et al., 2013 as noted above). In contrast, Jocelyn was one of 3 participants who had been physically present and included in the family during her sibling's treatments. Jocelyn stayed connected to her sick-sibling and her parents by being given the opportunity to take trips to Vancouver from her hometown of Kitimat and staying in Ronald McDonald house, a place which became a regular (and in reflection, "happy") part of her childhood memories. Jocelyn further described the medical professionals as very "welcoming" of her presence during her brother's cancer treatment and described how her mom encouraged her to be included in conversations with the doctors and nurses. Jocelyn reported feeling included in her family during her brother's treatments.

As I outlined in my literature review, *SuperSibs* offers creative suggestions for families to keep siblings involved and connected if the family is geographically separated, such as regular Skype dates and journals between family members. Interestingly, participants in my study who had lived in the city where treatment took place were not immune to feelings of exclusion during their siblings' treatments. Certainly from my participants' experience, well-siblings want to find ways to be included during treatment, regardless of geographical location. They want to be kept informed about their sick-siblings' wellbeing, and to help with and to provide care for their sick-sibling during treatments.

Maslow (1943) described the *need for self-esteem* being facilitated through opportunities to accrue a high evaluation of oneself that is based upon real ability. I think that a well-sibling provided with opportunities to play a "real ability" role in the family during their sibling's treatment, would, in this way, help to support or maintain their self-esteem. Maslow was of the opinion that self-respect and respect and appreciation from others (1943, pp. 381-382), and

purpose and value (1970, p. 45), were necessary for self-esteem. I think when the well-sibling is included they are given a message of “because you are respected you are being included,” which will communicate respect to a well-sibling. Further, Prchal and Landolt (2012) reported that siblings who are involved in the care of their sick-sibling have purpose and value. According to Glasser (1998), the need for power (experienced through self-respect, receiving respect from others etc.) is what well-siblings would be meeting through being included and informed (p. 38). Self-esteem is increased by the amount of power one has in a situation, and power increases through information and inclusion. Power can be gained, said Glasser, through being given information and inclusion (p. 39), thus a well-sibling who feels excluded will do what they can to regain some power in the situation.

Taken together these points support the importance of the well-sibling being included and given age appropriate information regarding their sick-sibling’s cancer treatments and journey. Being given information is an integral part of the inclusion process. I remind the reader about the quote I provided in Chapter 1 from the Canadian Cancer Society: “It’s common for both the parents and their child to feel that life has spun out of control. This can happen when you don’t feel you have all the information you need to make decisions” (2011). Information can therefore mitigate this chaos, and help provide well-siblings with not only a sense of inclusion during treatments, but also a feeling of security; they know what is going on and what to expect. When a sibling feels safe and included in the discussions and treatment of their sibling’s illness, perhaps they will feel like they belong in the family structure, no longer questioning “where do I fit in?” (DiGallo, 2003). Being included in and informed about the illness and treatment can also serve to create, what DiGallo described, as a bridge between the well-sibling and the sick-sibling. Well-siblings in my study described experiences of inclusion as well as exclusion during their sibling’s

treatment. Simmi's account of the way in which inclusion through involvement helped her find a role in her brother's care illustrates Ryan and Deci's (2000) needs of competence, relatedness, and autonomy. By finding some way to show and contribute to the caring of her brother, she felt capable; this interaction created relatedness between her and her brother. By coming up with her own unique ways to provide care for her brother, Simmi exercised ownership and control (sense of autonomy) in how she was contributing as a member of the family unit. As Emily so poignantly related: "*I just needed to be part of it.*"

THEME 4: The Need to Know that it is Normal to have Difficult Emotions and Uncomfortable Thoughts

Theme 4 relates to well-siblings' need to know that it was normal to feel difficult emotions (confusion, anger, frustration, jealousy) and to have uncomfortable thoughts ("*I wish I was sick so I could get attention*"). Theme 4 includes the subtheme, *The need for support exclusively for well-siblings* (e.g., peer-support programs and readily-accessible counselling support for well-siblings exclusively). Having difficult emotions and thoughts normalized and validated by peers, and receiving help (peer-support or individual counselling) in understanding and unpacking difficult emotions and thoughts, is helpful and validating in and of itself. Well-siblings need to know that these feelings and thoughts are normal to have, and this is best realized amongst peers or one-on-one with a professional helper or supportive adult in a safe environment exclusively for the well-sibling. All 7 of my participants had experienced uncomfortable emotions and thoughts during their siblings' cancer journeys.⁸ Not knowing that it

⁸ For example Emily described an emotionally charged scenario from her childhood where she got angry at her sick-sister and lashed out at her verbally. However, her anger and frustration was quickly replaced with feelings of guilt, as she said, "I remember feeling so bad afterwards." Without having had an opportunity to discover what her anger was telling her, she instead carried the guilt from her outburst.

was normal to have difficult emotions and uncomfortable thoughts resulted in well-siblings experiencing feelings such as regret, shame, guilt, and generalized negative self-judgment.

Theme 4 is consistent with the Patterson group's (2014) need domain labeled, *dealing with feelings*. As I mentioned in Chapter 1, other studies have tended to lump the experience of complex and difficult emotions under other themes. However, in my study, like Patterson's group (2014), I found sufficient evidence across my sample of the need to know that so-called "negative" feelings and thoughts are expectable, understandable, and therefore, normal, such that I was confident in abstracting out these data to fall within a standalone theme. From my perspective, almost all of my participants judged themselves negatively for feeling any emotion other than grief, sadness, and compassion for their sick-sibling—the "acceptable" emotions one might equate with a siblings' cancer diagnosis and treatment. Participants in my study communicated a strong need to know that these difficult feelings were normal. They also expressed a need for a safe place to share them. This is corroborated nicely by the item in the *dealing with feelings* domain of Patterson et al.'s (2014) SCNI, which asks respondents to rate their need "to be able to express how I feel about my sibling's cancer without worrying about upsetting people" (p. 657). To this statement, I would add "or myself," meaning that well-siblings receive permission to feel their difficult emotions without the fear of upsetting anyone, themselves included. When they know the feelings are normal they will not have to beat themselves up about them, but instead they can just feel them.

Wilkins and Woodgate's (2005) theme called *intense feelings* (i.e., the presence of sadness, loneliness, rejection, anxiety, anger, jealousy and guilt) pointed to but does not quite reach the specificity of the need to know such feelings and thoughts are normal. However, in their discussion of these emotions, Wilkins and Woodgate said that it is important to remember

that the presence of these emotions does not necessarily mean the well-sibling is troubled. They said, “in fact experiencing these feelings may be a very normal part of the cancer experience that siblings must encounter.” It was with this insight in mind I created the title of this theme in my study. I wanted to give the message that these uncomfortable feelings and thoughts are a normal part of the process, and, if necessary, may require support. It is my belief that siblings need to not only know that their difficult emotions and thoughts are normal, but also that their emotions and thoughts are telling them something (e.g., I feel angry because I need attention, I feel frustrated because I need to be communicated with, I wish I had cancer because I am missing love and attention from Dad and Mom).

The literature has also reported well-siblings’ inclination to internalize emotions due to: (a) not wanting to be a burden on parents who are already distressed and heavily laden with responsibility, or (b) holding a perception that their own problems are insignificant in comparison to those of the diagnosed child (Prchal & Landolt, 2012; Vermaes, Susante, & Bakel, 2010; Wilkins & Woodgate, 2005; Woodgate, 2006). Normalizing the difficult emotions of well-siblings and encouraging their expression of their anxiety, worries, and fears has been shown to help siblings adapt positively to the strains and stressors of having a sibling with cancer (Breyer et al., 1993). By feeling supported and safe in their emotional experience, siblings’ turmoil and upheaval is not only justified, but made just as valid as that of all other family members.

All of my participants expressed feeling angry and frustrated during their siblings’ illnesses, and three of them specifically said they felt hatred towards their sibling, and also felt guilt for having such feelings. This hatred echoed the research by Murray (1998) where one 14-year-old sibling expressed her anger in the following way: “I began to feel hatred for my sister...My sister stood bathed in the spotlight, and I’d been thrown in the corner” (p. 222). Guilt

was a prevalent emotion amongst my participants, and usually in response to the presence of some uncomfortable emotion, its denial, or its lack thereof. For example, Jocelyn said she felt guilty for not crying upon hearing about her sibling's diagnosis because everyone around her had been very upset. She remembered feeling bad because she did not cry. She also felt confused because she was told that her brother would be fine, so in her mind why should she be upset? Other participants shared their feelings of resentment, anger, and frustration; emotions that are well represented in the previous research (Alderfer et al, 2010; DiGallo, 2003; Houtzager, 2003; Wilkins & Woodgate, 2005). Participants expressed that, as adults, they felt relief in hearing that their feelings and thoughts at that time were understandable given their age, maturity, and situation. This was meaningful and helpful for me to hear. It seemed this recognition caused them to realize that having these feelings and thoughts did not make them "*bad*." However, in reflecting on this time, they went on to say how they had judged themselves as "*bad*" for having these emotions during the cancer experience. Furthermore, as I noted previously, participants felt relief following member-checking. Reading other participants' stories allowed them to learn they were not the only siblings who had these "negative" emotions.

One reason that this information was meaningful to hear from my participants, is that it has been suggested that siblings need to be encouraged and supported to experience and make sense of their emotions in order to have specific needs met (e.g., Wilkins & Woodgate, 2005). The inability or unwillingness to share their emotional stress causes greater anxiety, heightening their need for attention, love, and belonging (as described and discussed in Theme 1); needs that sometimes go unmet during times of trauma (Woodgate, 2006). Interestingly, in connection to Maslow's hierarchy of needs, the expression of anger, jealousy, and guilt as a response to the situations surrounding their siblings' illness, can indeed be considered a need for love and

belonging (Maslow, 1970, p. 44). Well-siblings have a need to understand that they are worthy of love and belonging, regardless of the difficult emotions and thoughts they have. As Glasser described, “don’t connect love with any specific behaviour. Make it clear that you love your children no matter what they do” (1998, p. 209). Beyond behaviour, well-siblings need to know they’re worthy of love no matter how they feel. This was certainly evident in the stories of my participants. Their anger was telling them that some core need was not being met. They felt angry with their sibling and that their sibling was sick, and also angry because they felt neglected. These feelings need to be met with patience, kindness, and an affirmation of love and belonging. In connection to self-determination theory (Ryan & Deci, 2000), it also seems plausible that well-siblings interpret the fact that their lives are impacted by the news and implications of a sibling’s diagnosis of cancer, as a threat to their sense of (and needs for) autonomy and control.

From the well-siblings’ experiences of needing to know their difficult emotions and thoughts were normal, it became increasingly clear to me that there was sufficient support for a subtheme called: *The need for support exclusively for well-siblings*. The following quote by Bree amalgamates both her need to feel her difficult emotions and thoughts without guilt, and her need to share them with someone who could offer non-judgmental listening:

Someone, that I could tell all my actual fears to. Without it being—or my anger too—without it being translated in a bad way...I was really annoyed and hated my sister at the time, for a lot of these things...So maybe if I had someone who was not in that social network, that is a safe zone, that you can just be like—like I am annoyed at her...letting out the emotions, words and not having to feel guilty about it. I think there was just a huge amount of guilt to have anything against her, or for her to be wrong.

Subtheme: The Need for Support Exclusively for Well-siblings. Six of the 7 siblings in my study expressed an explicit need for receiving help and support specifically for well-siblings separate from other family members, related to experiencing uncomfortable emotions and thoughts. Support exclusively for well-siblings will provide the venue to talk with a helping professional (e.g., counsellor, trusted adult) offering non-judgmental and empathic listening and support, or in a group of other well-siblings. Siblings often struggle to relate and communicate with their peers who have not had a similar life experience of cancer in their family. Other well-siblings are most likely to understand their perspective and empathize with the experience of uncomfortable, difficult, and confusing feelings and thoughts. In this way, siblings could serve as peer-supports (where “peer” refers specifically to other siblings of children and youth with cancer) to provide one another with relieving and normalizing emotional support. As Simmi said, *“If I ever told them [siblings who also had a sibling go through cancer] how I felt, I know they would understand because they went through the same thing I did.”*

Patterson et al.’s (2014) SCNI includes the domain *support from my friends and other young people*. Items within this domain include the needs: “the opportunity to spend time with other young people affected by their sibling’s cancer”; “to be linked with a social support network with others who share a similar experience”; and “to feel supported by peers who have a similar experience with cancer” (p. 656). Previous literature has also supported the need for specific supports for siblings, such as support groups, summer camps, online support systems, and individual counselling for the well-sibling (Hancock, 2011; O’Shea et al., 2012; Patterson et al., 2014; Prchal & Landolt, 2012; Wilkins & Woodgate, 2005). The nurses in the O’Shea et al. (2012) study recognized the need for families and well-siblings to have access to resources and help outside the hospital such as a summer camps and *SuperSibs* programs. Chung (2000)

reported that well-siblings who engaged in support groups were found to have positive changes in mood and behaviour, were more informed about the cancer, and overall reported that these types of environments created opportunities for siblings to discuss cancer more openly (as cited by Wilkins & Woodgate, 2005).

A further support for the importance of support specific to the well-sibling, is the research by Barrera et al. (2004) who reported that well-siblings who had high social support had fewer behaviour problems and symptoms of depression and anxiety. While it seems that Barrera et al. (2004) used the term “social support” in the broad meaning of including both emotional and instrumental support, the message of their finding for the importance of emotional support separately and specifically for well-siblings around difficult and complex feelings, remains. (Barrera et al. defined social support as any relationship with others that results in “feelings of attachment, security, being loved, being part of a group, reassurance of self-worth, availability of informational, emotional and material help” [p.104]).

In my study, Diana remembered how she did not want to share her experience with anyone at school, save for one friend, who did not know how to react. Well-siblings need connection with other siblings who understand what they are going through and who have shared similar life experiences. As Diana said, “*Siblings need to get together and have more opportunities to be supported.*” Participants in my study who had been provided the opportunity to engage in conversation with other well-siblings, described positive and validating feelings. Amelia, who appreciated attending *Camp Goodtimes*, also expressed a strong desire for a camp program that was strictly for well-siblings, as opposed to being mixed in with the sick-siblings. Her desire for this came from interactions at *Camp Goodtimes* where she did not feel like there was a place for her experience. She also noted how the fact that *Camp Goodtimes* only offered a

teen program for the sick-sibling, felt exclusionary. In other words, her experience at camp was over when she was 15, but her brother could continue on to the teen program, which was exclusively for kids who had been diagnosed with cancer, not their well-siblings.

One way of providing well-siblings with a supportive community is through camp programs, as evidenced through both Simmi's and Amelia's stories. Camp programs and sibling groups can offer positive and normalizing environments for well-siblings (Sidhu, Passmore & Baker, 2006). Well-siblings who attended a 4-day peer support camp for siblings of children with cancer, reported less psychological distress and anxiety, less isolation, and a greater awareness of their sick-siblings' cancer (Sidhu et al., 2006). Keeping in mind these positive attributes of being a part of this group, it is reasonable to suggest that being part of a sibling group would serve Maslow's (1970, p. 39) and Glasser's (1998, p. 34) needs for safety and belonging. Also by being part of the group, Maslow's need for self-esteem (1970, p. 46) and Ryan and Deci's (2000) need for relatedness are also met (e.g., by being part of a group they feel recognized, important, and validated). Participants' recommendations for well-siblings to receive exclusive and targeted support is understood and appreciated at a human level and, theoretically, from a needs theory perspective. Particularly when keeping in mind that many well-siblings reported feeling embarrassed and guilty about the difficult emotions they felt in reaction to their sick-sibling's cancer (and their aforementioned need for acknowledgment and attention [Theme 1]).

SuperSibs, as I noted above, is an online American based support system exclusively for well-siblings. It delivers helpful information to siblings and the people supporting them. While *SuperSibs* is American-based it does also support Canadian well-siblings, though none of my participants made mention of it. *SuperSibs* offers pertinent advice that acknowledges the well-sibling and offers helpful tips and ideas for ways of supporting the well-sibling. Hancock (2011)

endorsed the need for peer support as an important intervention for well-siblings, and recommended the use of modified SibShops, a model used when working with siblings of children with special needs by Meyer and Vadasy (2008; as cited in Hancock, 2011).

My participants also spoke about the value of one-on-one therapy or counselling support for well-siblings. Simmi articulated how it was helpful for her to be able to speak to someone who was really curious to know what “*Simmi’s perspective*” was on things. To Simmi, this made her felt seen for her own perspective and that she was a part of the picture. She found it helpful to have someone to go to who she felt really understood her, and she shared she felt a “*relief*” from not having to carry this experience all on her own. Amelia and Emily shared a similar memory and feeling of frustration of being given a colouring book in a hospital setting, and being asked to share their feelings in a way that they both found unhelpful. Amelia did share how eventually she found a therapist whom she appreciated speaking with because she felt like she was finally treated as someone who was going through their own experience, not just as someone whose sibling was going through something.

Leaving the last words to Emily, written on her feedback form was: “*I think the subtheme of the need for support exclusively for well-sibling is an important one.*”

THEME 5: The Need for Instrumental Support

All 7 participants reported needing instrumental support from different resources, the most notable sources were: (a) family and friends; (b) school teachers and other adults involved in their lives at the time (e.g., coaches); and family-level (as opposed to individual) support from (c) helping service workers and professionals. Instrumental support helps well-siblings (and their families) bridge the world they know with the new cancer world. Instrumental support can take form in a variety of ways: making efforts to keep well-siblings involved in sporting activities;

providing school work for siblings to complete while they are away with their family for their sick-sibling's cancer treatments; or guidance from helping service-workers to facilitate conversations within the family unit between and among well-siblings, their parents, and sick-sibling.

While instrumental support and emotional support are the two components of social support, instrumental support involves the tangible actions of social support that are perceived as helpful by those receiving social support (Semmer, Elfering, Jacobshagen, Perrot, Beeher & Boos, 2008). Whether it be through time spent with the well-sibling, extra help in the classroom, support on the volleyball court, or in receiving counselling help as a family, well-siblings require instrumental support. Instrumental support helps well-siblings to navigate the cancer experience by being able to maintain, as much as possible, what Wilkins and Woodgate (2005) referred to as their "own interests and activities," and what O'Shea's group (2012) described as "a normal routine." O'Shea et al. reported the observation, from a hospital perspective of paediatric oncology nurses, that families needed the support of outside resources beyond the hospital to help well-siblings cope during this time. *SuperSibs* recommends that siblings need to know they are not alone and that having instrumental support systems in place helps to let the well-siblings know they are not forgotten (SuperSibs, 2015). This, of course, is in alignment with the finding of Barrera et al. (2004) who reported the positive impact of social support on the well-sibling's psychological wellbeing.

I found and have reported 3 subthemes under this theme of needing instrumental support, namely: (i) family and friends; (ii) schoolteachers and other adults; and (iii) helping service workers and professionals to facilitate family-level communication and support.

Subtheme (i). The need for instrumental support from family and friends. Having the instrumental support of family members was impactful to the well-siblings in my study, who each reported the different ways their family was and was not present in their cancer experience. Instrumental support from family members looked like grandparents, aunts, and uncles all actively and pragmatically supporting and being present for the well-sibling. One sibling shared how her grandparents came from Mexico to look after her during this time, and another sibling had her uncle come and live with her when her parents and sick-sibling traveled away from home for cancer treatments. Participants spoke of the effort they witnessed these family members made. They actively helped the siblings by assisting them, for example, in keeping up with schoolwork and attending to keeping up with regular household tasks. These tasks were supported by Patterson et al. (2014) under the need domain of *practical assistance*, such as a need for “assistance managing daily tasks” and “to have people around me who can help out by taking over some of the things that my parent/s don’t have time to do anymore” (p. 656). For participants with more than one sibling, they said how their relationship with their other sibling who did not have cancer was also important to them. One participant shared how the absence of family members’ support during this time gave her the impression she could do whatever she wanted, and so she did, and this lack of support in her mind caused her to “*screw up*.”

Subtheme (ii). The need for support from schoolteachers and other adults. Some of the siblings talked about what it was like at school and in their communities being the “*sister of the kid who had cancer*” (Emily). Jocelyn remembered how she appreciated that a public health nurse had come in to speak with her class and explain what her brother’s cancer meant. For Jocelyn, she experienced a lessening of anxiety in not having to explain what cancer was and what was happening to her brother, and that it was out in the open. She said that she felt glad that

no one treated her differently, her friends acted the same as before, and that she did not feel pitied. Patterson et al.'s (2014) SCNI reflects the need for siblings to have help from teachers at school in their item probing the need “to have teachers and/or boss understand my situation and be more flexible” and “help concentrating on tasks at school...” (p. 656).

In contrast to Jocelyn, Simmi did not appreciate how her school approached the matter of her absence from school. While she was away with her brother during his treatment, Simmi's teacher, without Simmi's permission, told her whole class that her brother had cancer. Simmi returned to class to experience her classmates “*pitying*” and being very kind to her—classmates who only the week before had been mean and unkind to her. Simmi felt angry, embarrassed, and betrayed by her teacher. While for Jocelyn the classroom sharing created stability, Simmi experienced an inauthentic change in the way people treated her. When considering the two outcomes for Simmi and Jocelyn, it appears important parents, teachers, and well-siblings be collaboratively involved in school-based decisions. Research by Alderfer and Hodges (2010) suggested that social support from school-based individuals—especially friends, teachers, and classmates—is valued as important for well-siblings. Further, they reported that teacher-based support was associated in meaningful ways with better academic performance, less deviant behaviour, and fewer attention problems. Taking this previous research evidence, together with Simmi's experience where the teacher's support did not have the intended effect, it seems imperative that classroom support be individualized and jointly created with the individual well-sibling, rather than approached with a one-size-fits-all response.

Subtheme (iii). The need for family-level support from helping service workers and professionals. The need for family-level support from helping service workers and professionals showed up through the need for family counselling, and for support from medical professionals

and social workers at the hospital. Participants identified needing instrumental support from helping professionals such as talking with therapists and counsellors, either on their own or with their family. The difference between instrumental support and the emotional/existential support siblings sought under Theme 4's subtheme of *the need for support exclusively for well-siblings*, is that instrumental support of the family is collective, practical, and integrative as opposed to individual and emotional supportive care strictly for the well-sibling. Jocelyn reflected on the “*amazing*” staff at BC Children’s Hospital, Ronald McDonald house, and at *Camp Goodtimes*, and how very supportive they were to her and her family. Some of my participants spoke hypothetically about how they thought professional help could have instrumentally assisted their family

Instrumentally, helping service workers and professionals can support—and in many cases, relieve— well-siblings by providing support (instrumental and emotional) for their parents. For example, Bree was explicit in stating a wish that her parents had received their own support. O’Shea et al. (2012) described the importance of supporting parents to cope and, thereby, to support the well-sibling and sick-sibling. In consideration of all the needs and experiences of well-siblings, the provision of appropriate social support services is a necessity (Wilkins & Woodgate, 2005). Further, and I think respectfully in line with the qualitative researcher’s viewpoint, Wilkins and Woodgate (2005) stated how these social supports need to be informed by the wisdom and perspectives of well-siblings. As Diana aptly advised, “*Seek the outside help, because My God! You have a lot going on. So, you might as well have external people helping you out.*”

The need for instrumental support from different individuals in the well-sibling’s world connects to need theory. Satisfying the need for instrumental support touches on Maslow’s

(1970) need for *safety* in that having people present in their lives gives the siblings a sense of stability and continuity. Having people in their lives who care for them via practical and tangible support surely contributes to Glasser's (1998, p. 34) and Maslow's (1970, p. 43) need for *love and belonging*, and to Ryan and Deci's (2000) need for *relatedness*. I think instrumental support imparts the feeling of being companioned in the journey rather than abandoned. Through the help of outside supports, well-siblings are able to stay involved in their own interests and activities and therefore, present in their sense of self and competency.

THEME 6: The Need to Just be a Kid

Theme 6 is a unique finding of my study and relates to participants' expression of feeling sometimes burdened and overwhelmed by all the changes to their family, responsibilities, and their role as a child within the family. These feelings could result from a multitude of different circumstances; from having to make decisions possibly too big for their age and stage in life, to the perceived need to take care of and "fix things" and the people in their family, or the clear expectation to take on more responsibilities. The responsibilities well-siblings face range from taking care of household tasks, such as making dinner and babysitting other well-siblings, to taking on both their sick-sibling and parents' emotions. O'Shea et al. (2012) spoke to the importance of providing well-siblings with age-appropriate information; it seems fair to extrapolate from this that requesting/expecting age-appropriate responsibilities from well-siblings will assist in managing well-siblings' need to be "a kid." The SCNI instrument developed and validated by Patterson's group (2014), seems to attend to the need to be a kid in the need domain for "*time out*" and *recreation*.

In her study, Woodgate (2006) identified a theme called *committed to keeping the family together*. This theme was represented by well-siblings feeling responsible for keeping the peace

in their families. To do this they would avoid doing anything that could increase stress levels and cause further disruptions, such as not voicing their own concerns at the risk of causing more stress or pain for their already stressed parent(s) and sick-sibling. In my study, Elizabeth described her experience of taking on the parental role: *“I’m old enough I can walk in these shoes and be the mother figure in place of my mom who’s at the hospital.”* I am of the strong opinion that well-siblings be informed, and reassured, that “keeping the family together” is not their responsibility. I think of the danger of possible parentification (when a child becomes a caregiver) (Giammona & Malek, 2002; Hooper, 2012). A parentified child experiences a disturbance of generational boundaries taking on role reversals in either or both, functional and emotional roles (Hooper, 2012). This includes the child taking on parenting roles and responsibilities; being over-involved in decision making; being expected to deal with adult concepts and responsibilities (Giammona & Malek, 2002); and “sacrific(ing) his or her own needs for attention, comfort, and guidance in order to accommodate and care for the logistical and emotional needs of a parent and/or sibling” (Hooper, 2012, p. 323). The “Parenting tool-kit” resource on the *SuperSibs* website offers a caution regarding parentification. The toolkit cautions about the vulnerability of the older well-sibling most particularly for becoming the “third parent” in the family as a result of being loaded with too many adult responsibilities (Supersibs, 2015).

Giammona and Malek (2002) spoke in a general sense about the importance of countering parentification by allowing kids to be kids and giving them age-appropriate responsibilities. The *Supersibs* resource suggests that parents have people they can call on for help to take on these adult roles and responsibilities, so the well-sibling does not have to. Participants in my study expressed needing clearly delineated roles: they needed to know what their role was as the well child in the family, and what they could consistently rely on Mom and

Dad to be taking care of. The importance of delineated roles between children and parents is similar to the discourse in O'Shea's study (2012). The nurses described the importance of parents coping well, which allows the child to be the child, and the parents to be the parents. *The need to just be a kid*, therefore, is the inverse of the need to *not* be the caregiver, adult, home-keeper, or parent.

Woodgate (2006) also described the well-sibling's feeling of security being rocked by the experience of witnessing their parent's emotion in reaction to the sick-sibling's illness. This is a sentiment shared by participants in my study who were not sure what to do when they saw their parents crying and upset, sometimes for the first time in their life. This is not to say that parents should not show emotion in front of their children. Rather, it is for parents to be aware of their children's response and need for explanation or reassurance in the face of parental emotion, so they do not take on a feeling of responsibility for fixing or soothing their parent's emotions. The *SuperSibs* "parent toolkit" advises "it's OK for your children to see that you are experiencing a variety of emotions. Sometimes you may even cry together. Your children will learn from your example that feelings are valid."

According to Maslow (1970) illness in a family created a disruption in the feeling of safety, as what was once calm and stable is now in a flux of change and crisis (p. 39). When considering Maslow's needs hierarchy as it applies to the well-sibling's *need to just be a kid*, it appears that this need arises from a place of needing safety. Safety can be defined as having: "security; stability; dependency; protection; freedom from fear, anxiety, and chaos; need for structure, order, law, limits; strength in the protector; and so on" (p. 39). It is not surprising to see through the data in the extant literature and in the narrative data I collected in my study how the entire family, and of particular focus, the well-sibling's sense of safety, is rocked by the

impact of the cancer diagnosis. I believe this can be countered by the messaging of “You be the kid, and I will be the caretaker/parent. I may feel sad/mad/upset with what is going on with your sibling, but I want you to know you are not responsible for making this better. You are safe and you are loved, and you matter”.

It is easy to argue that the *need to just be a kid* appears to be in contrast to the *need for inclusion in treatment* (Theme 3). What I mean is that it could be interpreted that this need for just being a kid means that the well child does not want to be a part of their sibling’s treatment or cancer journey. But, I argue that it is more likely the case that parents, medical professionals, and other adults misunderstand or do not know how to navigate well-siblings’ seemingly competing needs to just be a kid *and* (yet) to also be included in the family during treatment (Theme 3). For example, the nurses in O’Shea et al.’s, (2012) study reported that some parents struggled with how much information to give or how to include well-siblings. Sometimes, this is done as a well-intended but—in my judgement—misguided desire to “let them be kids” by attempting to protect them from the harsh realities of their sick-siblings’ cancer. However, as previously outlined in the literature review and as participants articulated in my study, the need for inclusion is important to the well-sibling’s sense of belonging in the family (O’Shea et al., 2012). An example of this is Elizabeth who contented and included herself by—and prided herself on—getting her little sister’s belongings together. Loud and clear from my participants was that the need for inclusion in the family during treatment and the need to just be a kid, were distinct, separate, and mutually exclusive. Consequently, my participants outlined a need to be included in their siblings’ treatment and informed about what is going on, while at the same time getting to just be a kid by not having to take on responsibility for the outcomes and experiences of their family.

My discussion of age-appropriate information I provided earlier when discussing Theme 3 similarly overlaps with the need to just be a kid. This discussion asks caregivers to be perceptive and sensitive to the well-sibling's personality, maturity level, and needs when delivering information to them. I am suggesting therefore that part of letting the well-sibling "be a kid" is giving them age-appropriate information. For example, Jocelyn, who had been 12-years-old at the time, appreciated being invited and given the choice to decide how much and how often she would go to Vancouver to be part of her brother's treatments. While Emily, who had been 10-years-old, said that the decision her parents gave her by asking if she wanted to be in Vancouver with them for her sick-sister's treatments or to remain on Mayne Island, was a decision that "*should [never] have been put on a 10-year-old, because like it has caused a pretty big divide in our family ... I just wanted to be a 10-year-old.*" At the same time, for adolescent well-siblings, age-appropriate decision-making and responsibilities are necessary and important for the development of autonomy (Hooper, 2012), a central task of adolescent development (Pruitt, 1999, p. 46; Ryan & Deci, 2000). These two points are nicely illustrated with the stories of Jocelyn and Emily, who developmentally were at different places in their desire and ability to make these decisions. (I speak further to this matter of the symbiotic nature and overlap of themes on p. 163 below.)

There exists a fine balance of providing well-siblings with the safety that things are under control as proposed by Maslow (1970, p. 39) in conjunction with age-appropriate freedom and independence in their need for autonomy, as related to self-determination theory by Ryan and Deci (2000). Similarly, there also exists a fine balance of helping well-siblings to meet their independent needs for being a kid and for feeling included in the family at all times, treatment times included.

THEME 7: The Need for Humour, Laughter, and Light-heartedness

Theme 7 is a second unique finding of my study and all the participants in my study shared specific stories about their need to be able to laugh and find moments of light-heartedness through this difficult experience. This did not mean that they laughed in the face of cancer, but rather they laughed in spite of it and with their sick-sibling and parents.

In my search of the literature I did not come across any similar findings. Close however to this need, Patterson et al. (2014) did include the item “the need to have fun” under their domain of “*time out*” and *recreation*; and the item “to be able to still have fun and enjoy myself without feeling guilty” in their domain of *dealing with feelings* (p. 656). Fun can be defined as “something that provides mirth or amusement,” and mirth is defined as “amusement, especially as expressed in laughter” (Merriam-Webster, 2014). Therefore, through dissection of the meaning of the word *fun*, fun can be considered to include laughter. However, I believe it is important to take note of my participants’ explicit need for humour, laughter, and light-heartedness. Doing so provides the insight that “time out” is more than just (recreational) fun, it is also about finding the humorous in the less-than-funny realities of the situation. For example, Jocelyn told me about how her brother’s hair loss was something they (she, her mom and brother) were able to find humour in through his mischievous behaviour. In my mind, distilling this as a need for fun could be interpreted as insensitive, how can losing your hair be analytically coded as fun? However, considering ways in which we can laugh, bring humour, and light-heartedness to unpleasant and miserable experiences, seems less insensitive. Indeed, *SuperSibs* include the recommendation on their support tips for well-siblings, “remember, it is ok to laugh...[laughter can be] stress-relieving for everyone.” Beyond this connection to *SuperSibs* and the connections to Patterson et al.’s (2014) items, I could not find examples in previous

research that spoke specifically to the need for humour, laughter, or light-heartedness as a need of well-siblings.

When I think of childhood cancer and humour, the doctor Patch Adams and the Gesundheit Institute comes to mind. Patch Adams, made famous by the blockbuster movie, is a real life clown, medical doctor, and social activist dedicated to changing the American healthcare system. He believes that laughter, joy, and creativity should always be a part of the healing process (Adams, 2015) and there is substantial evidence to this effect in connection to children with cancer (Bombeck, 1989, as cited by Dowling, Hockenberry, & Gregory, 2003). For example, in their study, Dowling et al. (2003) reported a direct relationship between the child with cancer's sense of humour and their psychosocial adjustment to the cancer; such that, children who reported a higher sense of humour also reported greater psychological adjustment, regardless of the amount of cancer stressors. Elizabeth related a story of light-heartedness that indirectly speaks to the benefit of families to ensuring that they arrange for and create times to play and share good times together. She described a memory from a summer road trip her family took in between her sister's chemotherapy treatments:

We got really close and went to Green lake and went swimming. Just, just, random little things that I remember. Those were actual good things that happened during that time, that have fed into this really jovial lifestyle that our family has.

She laughed as she reflected on another memory of her little sister dancing in the back seat of the car. They had just eaten an ice cream bucket full of cantaloupe and her sister had taken the bucket and was wearing it as a hat:

She never fully lost her hair, but she had little wispy pieces all over the place and I have no idea what she was doing, but she was dancing and, living it up and there is this girl

who is still going through chemo and has a shunt in her chest from every week and she is dancing and living life as if nothing's changed and I think partly because she was so happy it made it so much easier on my parents.

In Elizabeth's story telling I hear how the power of her sister's light-heartedness and silly behaviour with the ice-cream bucket on her head lowered her own stress levels by way of seeing how it made it easier on her parents. Interestingly, I observed that in all of the participants' stories about humour, it had been their sick-sibling who instigated the playfulness and laughter: Jocelyn's brother found mischief in his hair falling out, Simmi's brother made cancer jokes, Diana's sister laughed at the awkwardness of hospital gowns, and Elizabeth's sister played silly with an ice cream bucket. In contrast Emily expressed a feeling of loss for not being able to remember any fun or "positive" memories from this time. She shared a disappointment that her difficult emotions had so heavily coloured her memories she could not remember any positive ones, she said "*I know that they were there, but I don't remember them*".

On examination it seems that it is often the sick-sibling who initiates the laughter, and thereby gives permission to parents and well-siblings to giggle through this painful process. I think that because the exchange of humour is somewhat contractual in all of my participants' stories, the need for humour, laughter, and light-heartedness connects to the Ryan and Deci (2000) need for relatedness. Shared humour, laughter, and light-heartedness also meet the needs of Maslow's (1943, p. 43) and Glasser's (1998, p. 33) for love and belonging, and Glasser's theorized need for fun (p. 41). For these reasons, well-siblings need laughter, humour, and light-heartedness between themselves, their sick-siblings, and their parents.

While the research by Dowling et al. (2003) reported the benefits of having a sense of humour for the sick-children themselves, thereby indicating a purpose and place for humour,

laughter, and light-heartedness in the experience of childhood cancer; I now suggest the benefits extend beyond the sick child to their well-sibling and parents—to the family as a unit. It could be that by supporting the sick child to retain a sense of humour, the wellbeing of the sick child and their well-sibling, parents and family unit, will all benefit in the short and long term. The enduring benefits of humour, laughter, and light-heartedness are clearly evident in Jocelyn’s description of the lingering effect of her brother mischievously giggling and dropping his hair on his mom when she said: “*Thinking of that [story] makes me so happy.*”

Redundancy and Overlap across Themes

It is true that there is interrelatedness and symbiotic relationship amongst my thematic findings. I have previously noted this. I am convinced however, that, for the most part, all human needs share a symbiotic nature. Maslow’s hierarchical depiction of need levels demonstrates the interrelatedness and interdependence precisely. While technical standards of qualitative rigour define themeness as discrete and mutually independent themes, I feel strongly that had I collapsed across and abstracted out my data into fewer non-overlapping themes, much important and practically meaningful insight, findings, and recommendations would have been hidden at best, lost at worst. For example, I made the point earlier that (and provided the rationale for why) I had been intentional in keeping and reporting well-siblings’ expressed need for and depiction of *family communication* (Theme 2) separate from their need for *inclusion in the family during treatment* (Theme 3). That said, I provide three examples to briefly illustrate some of the overlap and interrelatedness within and across my thematic findings.

The Need for Attention and Acknowledgment and the Need for Instrumental Support. Elizabeth, Bree, and Simmi all shared how lack of attention from their parents towards

their own interests in sports and in school had left them feeling neglected and, in some cases, saw them drop out of the activity because their parent was not available to them.

Bree recalled one of her friends remarking that she must be enjoying all of the attention she was receiving because of her sister's illness, a remark that left Bree feeling sad, angry, ashamed, and misunderstood. The attention Bree "craved" and really needed was about her own struggle and one of the ways that this played out for her was through needing help and support in focusing on her schoolwork and goals. Bree's need for support in school was specifically spoken to by Patterson et al. (2014) under the need domain of *practical assistance* with the need-item for "help concentrating on tasks at school..." (p. 656).

The Need for Open and Honest Family Communication and the Need for Instrumental Support (subtheme: family-level support from helping service-workers and professionals). Honest and open family communication is a tricky business in families during a crisis that is defined by Patterson (2002) as "a period of significant disequilibrium and disorganization in a family" (p. 351). Patterson goes on to say that a crisis can be a turning point for a family to either continue functioning in an adaptive manner and learn new skills or go in the other direction and have their functioning disintegrate. There were several items on Patterson et al.'s (2014) SCNI that aligned with how my participants spoke about their need for communication in their families. My participants spoke about not knowing how to talk with their sick-sibling, parents, other family members, friends, teachers and others about how and what they were feeling. With this information, it seems apparent that families need to be given support and assistance in how to engage in honest and open communication. (The keen-minded reader will also have noted a third level of overlap of the above with the Need to Know That it is

Normal to Have Difficult Emotions and Uncomfortable Thoughts [and it's subtheme: The need for support exclusively for well-siblings]).

The Need for Open and Honest Family Communication, the Need for Instrumental Support, and the Need for Inclusion (through information) in the Family during

Treatment. Elizabeth's description of how she remembers wishing her parents would talk with her to explain what was going on and what was going to happen at the time of initial diagnosis, is an example of this three-way symbiotic relationship among my thematic findings. She needed communication, instrumental support and to be included all at one time. This is in keeping with the emphasis Patterson et al. (2014) placed on the importance of open and honest family communication in terms of information giving, specifically well-siblings need "to be informed about my sibling's condition—**good or bad**" (p.657) (my emphasis).

Auxiliary Findings

The following topics were identified as notable in my participants' transcripts, but not made into themes as they did not reach endorsement rate of being identified by 4 or more participants. As such, they were not submitted to the participants for formal review and endorsement. However, I did think that they were important to include in this auxiliary section to honour and truly conceptualize the lived experiences of the participants. It is also important to include these pieces of data because I conducted convenience sampling and did not reach data saturation, but they represent potential points for future inquiry.

The Need to Not Be Pitied

Three of the siblings identified and noticed the role of pity in their lives. Two reported a strong dislike for it, and another shared how she appreciated that her friends did not pity her. One participant described feeling "terrible", "awkward", and "strange" when she knew people felt

bad for her. Another noticed herself not sharing her experiences with other people because she feared that they would pity her. Lastly, one more sibling reported that she appreciated how her friends did not pity her, and treated her in the same way as before.

The Need for the Sick-Sibling to be interested in the Well-Sibling's Life

One sibling expressed feelings of frustration as she noticed her relationship with her older sister changed. She felt like her sister never listened to her and that this is a problem that still plagues their relationship. She described how she would be able to describe every detail of her sick older sister's life, but that she believed her sister knew nothing about her life.

The Need to Not be told "it's in God's hands"

One participant expressed anger about people in her religious community approaching her and her family and saying how, "God was going to do his thing." These types of remarks made her feel very angry. She recalls knowing that people were trying to be empathic, but she found them aggressive with the way they presented their opinions and pressed them on her. From these interactions the participant reportedly became less interested with religion.

I believe my 7 thematic findings taken together with the auxiliary findings provide further confirmation of the gap in the literature and need for research identified by Alderfer et al. (2010); Alderfer and Noll (2006); Buchbinder et al., (2011); and by Wilkins and Woodgate (2005); namely that the well-siblings of children and youth diagnosed with cancer have needs that require research attention. When contrasted against the extant literature, it appears that there are at least two unique discoveries in my study as well as findings that are corroborate previous research. Considering my participants' expressed needs in terms of need theories also helps to understand how well-siblings' needs can be met and why it is important to their wellbeing that these needs are met. Ryan and Deci (2000) described needs (both psychological and

physiological) as “an energizing state that, if satisfied, conduces toward health and well-being but, if not satisfied, contributes to pathology and ill-being” (p. 74). According to Ryan and Deci (2000) wellbeing and integrity in life can be experienced when an individual has their needs for autonomy, relatedness, and competence met, and this is my hope by presenting the needs of the well-sibling that we can use this information to contribute to supporting their wellbeing. I wholeheartedly agree therefore with Wilkins and Woodgate’s belief that gaining further understanding of well adolescent siblings’ individual experiences may shed light on how to acknowledge, take note of, and consider the well-sibling experience.

Limitations of the Study

Limitations of the study is that my pool of participants were all females, which was unintentional, but could also be considered a strength in that it offers a unique snapshot of what it is like to be a female well-sibling. However, a sister-only sample was not my intended focus, and when considering the desire for “transferability” (Krefting, 1991) one could argue and perhaps be curious if these needs would be similar for a male population. I did actively try to recruit male participants as I had been given permission to contact a potential male participant, but never heard back from him. Further, I asked one of my participants to please invite her other well-sibling who was male. She shared later that he declined participation. I do not have any specific information about why it was difficult to recruit male participants. I will speak to gender further when I discuss future areas of research.

A further sampling limitation is that all of my participants are British Columbians (though one was living out of the country when I interviewed her). This type of homogeneity could weaken the transferability of my study because the services and programs in other provinces and countries will be different. Another limitation of my sample is the size of my

study. I interviewed 7 well-siblings, which, from a qualitative phenomenological research study standpoint, is considered trustworthy (Creswell 1998, p. 64). However, I cannot honestly say that my data reached saturation. Data saturation implies that enough stories have been gathered that themes start repeating themselves and added information does not add new understanding about the phenomenon being explored (Kirby, Greaves, & Reid, 2006). I know I did not reach data saturation because I have auxiliary findings that failed to reach the criterion for themeness. Due to this being a master's level thesis there were time constraints around how long I could recruit participants of this small population for, timing and the unique population as contributing to why it was difficult to achieve data saturation. However, I remind my reader that I guided my sample of 7 participants around the suggestions of Creswell (1998, p. 64) and Guest et al. (2006, as cited in Mason, 2010) who stated that a sample size of 6 participants is often sufficient to reach saturation in a population with a high level of homogeneity (all were adolescents when their sibling had cancer). However, the findings of my study could serve to inform further quantitative studies.

Another limitation and area for future research is the fact that I focussed specifically on the needs of siblings whose brother or sister lived through the cancer experience. I did this based upon the belief that bereaved and non-bereaved siblings might retrospectively articulate having had differing needs following and during their siblings' cancer diagnosis and treatment. Therefore it would be interesting to complete a comparison study looking retrospectively at the needs of bereaved adolescent siblings. An example of this is that in my review of the literature, I noticed (and reported in Chapter 1) the item on Patterson et al.'s (2014) need domain of well-siblings' need for "help with feelings about the possibility that my sibling with cancer might die" (p. 657). While this need did not come up for my participants, I thought it is important to remind

the reader about this need specifically, as it is, I think, a unique finding of my sample, and possibly a limitation. I believe that is because the sick-siblings of all of my participants lived, therefore the discussion of death was not as present as it might have been had I spoken to participants either during their sibling's illness when outcomes were not guaranteed, or also if I was talking to a sample of bereaved siblings.

While I do believe there is overlap in the needs of bereaved siblings and non-bereaved siblings, I also think there are significant differences in their experiences and non-bereaved siblings are often overlooked. For example, some oncology summer camps offer camping events strictly for bereaved siblings but will not offer an exclusive program for siblings whose brothers and sisters are still alive. I also learned from one of my participants [as mentioned in my methods section] who not only had a sibling who had lived through cancer, but who also had another sibling who had died from a non-cancer related death after her brother's cancer treatments were over. She provided me with rare insight into her experience of being both a bereaved sibling and having a sibling with cancer. She shared that the difference was when she was asked about her sister who had passed away she was asked "how do you feel that this is happening to you?" While when she was asked about her brother with cancer she was asked, "how do you feel that this is happening to your sibling?" This distinction I think sheds a bit of light on the experiential difference in her identity as a sibling. In my understanding of her story, as a bereaved sibling she was given more attention for what her experience was like, whereas when her brother had cancer the attention was focussed on him.

It can certainly be argued that a limitation of my study is that I did not employ a family systems lens to explore the needs of well-siblings. My intention was not to negate the power of systems theory, an approach I rely on heavily in the counselling work that I do. However, it has

been my experience that in order to see the whole family dynamic I need to understand individual parts of the system to go forward and understand the whole picture. That being said, this research presents findings that can help in supporting the needs of well-siblings, while keeping in mind that of course the sick-sibling, parents, and family as a whole have needs that deserve attention as well.

Lastly is the fact that I am a novice researcher. While I have had previous experience working as a research assistant in other researcher's (primarily quantitative) studies, this was my first experience conducting my own research. With hindsight-wisdom there are things that I would change about how I conducted the research, such as using the participants' clustering maps from our interview as a piece of data for triangulation. Instead I chose to let these be used merely as process tools, so that participants did not feel stressed about how I would be interpreting them and could be candid and relax. However, even though this is my first independent study I was able to support the trustworthiness of my research through careful mentoring by my supervisor who guided me in every step of the process, through development, implementation, analysis, and interpretation of my research. I also took three graduate level research methodology courses, all of which were foundational in my development as a qualitative researcher.

Strengths of the Study

There are at least four strengths of this study. First, is the homogenous sample of non-bereaved adults speaking retrospectively to their adolescent well-sibling experience. To date, little research has focussed on the needs of specific age groups of well-siblings. In Wilkins and Woodgate's (2005) systematic review of 27 qualitative studies they criticized the studies for often using a generalized sampling process, combining siblings across ages and developmental

stages. They argued that this type of heterogeneous sampling makes it difficult to make inferences based upon the developmental level of the sibling. This type of heterogeneous sampling continues whereby the needs of a 24-year-old are lumped in with that of a 12-year-old, as exemplified in Patterson et al.'s (2014) development of the SCNI. In Wilkins and Woodgate's review of qualitative studies concerning the well-sibling cancer experience, only 1 of the 27 studies had focussed specifically on the age group of adolescence. By being specific to this age category of well-siblings, my findings shed light onto the unique knowledge of the needs of adolescents. Looking exclusively at adolescent siblings and focussing on non-bereaved siblings created homogeneity in my sample, as recommend by Wilkins and Woodgate.

Maintaining the non-bereaved exclusion criterion was difficult. I received interest to be involved in the study from two siblings who were bereaved, and I was also contacted on behalf of one bereaved sibling's parent, who asked me to change the eligibility of my study because she believed her bereaved children would be able to contribute greatly to what I could understand about siblings. I thanked her for contacting me, and acknowledged the wisdom and experience I believed her children had, while at the same time explaining my need to focus exclusively without the intention of excluding. Fortunately, I knew a researcher who was focussing exclusively on the experience of bereaved siblings, so I could direct these prospective participants to that study.

Second, my study was retrospective in design. From a design perspective, the fact that my data are retrospective can be argued to be a limitation of the study. Retrospective memories are subject to memory bias, time, distance, and to the experience of the storyteller (as I reported in Chapter 2). On the other hand, it is also argued that retrospective findings may prove more beneficial because adults possess greater self-knowledge than children and adolescents when

reflecting on their experience (Pompeo, 2009). Lehna (1998) also suggested that the retrospective vantage point of adults might be able to lend insight and valuable information in the form of advice giving to other well-siblings. She suggested this is due to adults being more articulate than those who were younger and concurrently immersed in the experience. This is a point which some of my participants supported as they reflected that they believed as adolescents they would not have been able to articulate what was going on for them in the moment. As I also said in Chapter 2 (under the *Research Design* heading, and in the discussion of *retrospective points of view*) I value the capacity of hindsight to carry wisdom. I strongly believe that a retrospective study offers sensitive, meaningful, and useful information about the lived experience of well-siblings.

Third, I believe the degree of reflexivity I engaged in throughout the entire research process strengthened my study. I was willing to change as a function of listening to my participants. For example, in the experience of honouring the voice of my participant who disliked the use of the word “survivor” I allowed myself to consider the meaning of the word, leading to what Haverkamp and Young (2007) described as the fusion of horizons. In the years following my “dance” with cancer, I used the word “survivor” to identify myself as someone who is still living after receiving treatment for cancer. I had not considered changing my use of the word, nor questioned the deeper meaning of it until my participant shared her thoughts about the term “survivor.” I was open to hearing how she felt about the word and, along with other participants’ reflections on the word when I later sent an email asking for their thoughts. Through these interactions I have made a conscious choice to let go of using the word “survivor” both in my writing up of this study, and personally. In place of the word survivor I now choose to describe myself as “a person who lived through cancer” rather than as a “survivor” of cancer. I

acknowledge that in Chapter 1, most particularly, I do have places where I describe childhood cancer survivors, but it is often in reference to previous studies where the researchers have labelled their participants this way (e.g., Buchbinder et al. (2011) referred to their sample as *sibling survivors*), a point which I will discuss below in my implications. I believe that inasmuch as my reflexivity in the research process changed me and opened my mind as a researcher—exemplified here by way I engaged in the reflexive challenge of confronting my use of the term “survivor”—is also an important strength of my study.

A fourth strength of this research study is the positive impact that participants expressed through their involvement with the research. Participants shared with me during and at the end of their interviews that they, “*had never realized*” and were “*(now) more aware*” of how the cancer experience had impacted them. Literature reveals that often siblings maintain a belief that their own problems are insignificant in comparison to that of the affected child and their parents (Prchal & Landolt, 2012; Wilkins & Woodgate, 2005). My intention and hope in conducting this research study—irrespective of its findings—was that we would offer validation to this often forgotten population by informing well-siblings that their voices and stories were significant and important. Creswell et al. (2007) pointed out that when researchers “collect stories, they ... provide ways to be useful to the participants” (p. 244). I wanted to be useful to my participants and I believe that the narrative-data collection process was, for the most part, a validating one for the well-siblings who I interviewed. One participant wrote on her member checking form, “*I am just so thankful you are doing this and so incredibly honoured to be part of it. Thank you.*” Another sibling followed up in an email to me saying, “*Thank you for letting me be a part of it! I learned a lot about my experience just from being able to share it with you!*”

It appears that benefits can be derived from feeling heard even when it is many years (sometimes 10 years or more) later. This is similar to DiGallo's (2003) study in which two-thirds of the participants self-reported a positive impact of their participation in his study; which was a narrative retrospective study involving siblings and children who had been diagnosed with cancer. None of DiGallo's participants reported any negative effects from being a part of the study, the same has been true of my participants. Several participants reported in follow-up communication with me that the experience of being involved in the research helped them see themselves differently (in a positive way). Amelia reflected that through her involvement in the research she had a realization: "*I guess I surprise myself that I am bit stronger than I thought I was.*" I asked Jasmine, my little sister, what it was for her to be involved in the research for the pilot-interview and for consultations. She shared with me: "*I feel important and that I am not forgotten. I've learned to forgive myself and now know that I am not a jerk for feeling what I felt and the way I behaved when you were sick. I feel heard and like my story has been told*" (J. Stonebridge, personal communication, January 11, 2015).

Insights and Implications for Counsellors, Health Professionals, Family Members, Friends, and School Teachers

Overall, and with great brevity, I suggest that the 7 needs I reported as findings are meaningful to and feasible for implementing in clinical practice, within the family, and in community relationships and settings. Clinically speaking I believe this information would be helpful to: counsellors, health professionals and service/agency workers working with families dealing with childhood cancer. Within the family these findings could be of benefit to parents, siblings, extended family, and to community relationships and settings. I believe well-siblings' peers, classroom teachers, coaches would all find usefulness in this information.

One example of looking forward in implementing this information into practice would be the creation of specific sibling support groups (as indicated by Theme 4's subtheme: *The need for support exclusively for well-siblings*) and the possibility of creating an annual camp dedicated specifically for the well-siblings. The importance of peer-sharing in order to cope with and understand difficult emotions is essential for the youth whose sibling has cancer. This is an area that is largely underserved in British Columbia, according to Kristina Jackson, child life specialist in paediatric oncology at BC Children's Hospital (BCCH). She reported that at present there was only one specific support group for well-siblings that ran occasionally at the hospital, but it was a closed group and was only for siblings who were labelled as "high-need." In speaking with Ms. Jackson regarding the available supports for well-siblings, she shared, "I think we are underservicing the siblings in the programs at BCCH. Best practice would include having well-siblings better involved in programming with someone attending to their specific needs. At present we are definitely missing this right now, and sadly do not have anything formal for siblings in place" (K. Jackson, personal communication, March 18, 2015).

Ms. Jackson mirrored what the participants in my study told me in our interviews: well-siblings need places and spaces within which they can connect, share, learn, and feel supported and understood. It is my belief that the findings of my study, in combination with the extant literature (e.g., Hancock, 2011; O'Shea et al., 2012; Patterson et al., 2014; Prchal & Landolt, 2012; Supersibs, 2015; Wilkins & Woodgate, 2005) and the anecdotal apparent lack of resources in our community, create a valid argument for this population's need for these types of groups and supports. In the creation and implementation of these programs it is essential that the wisdom of the experts be taken into consideration (I remind my reader that in my eyes the experts are the well-siblings). I also believe that it is necessary for thorough program evaluation

(which I speak to under the heading *future areas of research*) and staff training to take place. I will elaborate on this last point, regarding education and training, in the subsequent section.

In order to create effective support programs for well-siblings, it is my opinion that professionals who are facilitating them need to be provided with adequate training and educational opportunities. I suggest that it would be beneficial for professional development training opportunities to be created for counsellors, social workers, nurses, cancer agency volunteer workers, and teachers. In my graduate training in Counselling Psychology, I completed several courses in which I learned about program development, implementation, and evaluation, and received training, clinical practice, and supervision in group facilitation. I would like to utilize this education for further work with well-siblings and helping professionals. I envision creating daylong training sessions with interactive seminars: these seminars would involve a distillation of the information from my research combined with other research and organizations (e.g., *SuperSibs*); practice information from guest speakers such as child life specialists, social workers, oncology nurses, and counselors; and anecdotal insight and wisdom from parents and well-siblings willing to be guest speakers and present first-hand accounts of the well-sibling experience. The combined display of research, insights and perspectives would provide a comprehensive overview of the experience and needs of well-siblings. Such events would broaden and stimulate conversation about how to support well-siblings at diagnosis and during treatment of sick-siblings. Further, I think it would be of benefit for this information to be an integral part of any psychoeducational seminar/workshop for parents of newly diagnosed children and youth.

As a researcher I believe it is my ethical responsibility to disseminate and to make the findings from my research accessible and useable to the community at large. I want it to be

helpful not only for the siblings who have participated in the study, but also for future well-siblings, their families, and the people who will help support them. Therefore in a knowledge mobilization effort I have created (with the guidance of my supervisor and a professional film company) a short video entitled *You Matter*. *You Matter* is a short educational video featuring some of my participants, which shares the findings of my research in a way that is easily accessible (much more accessible say than having people read this 200 page thesis document). My ultimate intention is to share the completed video with different cancer community stakeholders such as BC Children's hospital, The Canadian Cancer Society (*Camp Goodtimes*), *SuperSibs*, and organizations such as Childhood Cancer Canada. The video will be made viewable on the public domain via Vimeo or Youtube. It could also be distributed through informational pamphlets, which would provide the URL and be disseminated on hospital oncology wards; in doctors, counsellors and other support service worker's offices; and provided to high school principals/teachers and to university and college counselling centres. The intention of this dissemination is to spread the message that the well-sibling has needs in the cancer journey too and that they matter.

Speaking more broadly now but most specifically to counsellors, it has become apparent to me how relevant this work is to other areas of interest beyond just families impacted by a childhood cancer diagnosis. In my graduate training I have had the opportunity to be trained in different settings and it has been through these experiences, that I have come to realize, and appreciate, the weight, value, and transferability of my thesis work and findings. For example, in my practicum at the Eating Disorder Program of Southern Vancouver Island, I was exposed to Family Behaviour Therapy for youth with anorexia. The siblings of these youth are considered integral players to the family's therapeutic process. I found myself surprised by the relevance my

research had to this population's siblings, and recognize how it may be helpful in future counselling work with other families, children, and youth. Parallels I saw when considering working with future families in a mental health setting, include the way that there is typically the one identified client (e.g., the child with the eating disorder). However, these children and youth are also likely to have siblings who will be impacted and in need of attention, not unlike that of well-siblings of children and youth with cancer. I include this similarity in my practice in working with eating disorders as a point of consciousness-raising for those working with any family struggling with mental health issues. When the health and wellbeing of a child or youth in a family is severely compromised, all members of the family will be impacted in different ways and have a role and voice that need to be heard.

In thinking of the knowledge gained from this research study and implications for future counselling practice, I would also like to bring up the awareness of gender implications and the well-sibling. As aforementioned from previous literature, there may be an interaction between age and gender in how the well-sibling responds and adjusts to the sick-sibling's diagnosis and cancer treatments, and to the ensuing changes within their family structure and functioning (Alderfer et al., 2010; Houtzager et al., 2005). While I do not have data from my research that points specifically to this impact, I do think it is important to bring awareness to sex and gender differences that could play out with well-siblings, as my participants were all female. Houtzager et al. (2005) reported that female well-siblings reported greater levels of post-traumatic stress, anxiety, and social problems than male well-siblings; older sisters were also significantly less satisfied with relationships with family members, peers, and others. I restate this information here as a reminder of the possible gendered implications and gender-typing that may occur for brothers and sisters in any family when a sibling is struggling with illness.

In the interests of clinical practice, research, and social parlance, I think it is also of significance to point out an implication of my experience of my participants' reactions to the word "survivor." In cancer culture, the term "victim" has been exchanged for what has been valued as a more "positivistic" term: "survivor" (Bellizzi & Blank, 2007). In their 2011 review of publications relevant to the impact of cancer on well-siblings, Buchbinder et al., in the context of a family systems framework, chose to refer to siblings as *sibling survivors* and they deemed this as a positive label. They believed the label acknowledged siblings as part of the family unit, which was faced with the difficulties of cancer survivorship. In their words: "we have adopted the term sibling survivors to highlight the unique experience and needs of this growing population" (Buchbinder et al., 2011, p.133). Buchbinder et al. do not discuss what steps they took to decide upon this label, and whether or not the population they were labelling was consulted on its creation. The participant in my study who shared how her family did not like the word survivor was clear in her message: Given that she and her family had met many children who did not survive their cancer, she considered the word "survivor" to imply that these children (and their siblings) were somehow "less than" for dying from cancer. As I noted earlier, to honour her voice I emailed all of the other participants asking how they felt about the word "survivor", and told them how I was thinking about dropping the word "survivor" from the title of my thesis. Four siblings responded to my email, all supporting the changed title, and went on to provide their thoughts about the word. For example, Elizabeth wrote how her now-recovered sister resonates with the word survivor but that she (Elizabeth) could, "*understand why people don't like it. There's the fact that saying "survivor" and "winning" the "battle" with cancer makes it sound like those who have passed away and "lost the battle" were somehow weaker and not as resilient. I don't really see it that way, but I can understand the reasoning. So yes, I support the*

shift away from it.” Out of interest, I also looked up the definition of and synonyms for the word survivor; synonyms which included: left-over, debris, scraps, and (even) trash. Once I read these words I was even more committed to omitting the word survivor from my thesis title. I changed the title of my research from: *What About Me? Exploring the Needs of Adolescent Siblings of Childhood Cancer Survivors* to *You Matter: Retrospectively Exploring the Needs of Adolescents who had a Sibling with Cancer*. I provide this awareness as an important reminder to clinicians, researchers, family and community members to pay close attention to language when counselling, working, helping, supporting, or talking with children and families dealing with cancer. As a social constructivist with a narrative lens I do believe in the meaning, weight, and importance language carries and creates, and that we as a society create the labels, terms, diagnoses and categorizations that for some may be empowering and for others shame-inducing, limiting, and dismissive.

From the auxiliary findings I make the recommendation that what well-siblings want is empathy, not pity. Pity, as explained by the siblings in my study, is the sense that people felt sorry for them. Well-siblings need (and want) to feel valid; they need empathic care and concern. The difference might look like actively supporting the well-sibling by saying something like “How are you doing? I want to know about you and what’s going on for you?” This in contrast to, “How is your [sick brother or sister’s name] doing, oh I feel so bad for your family, you poor thing,” or being given platitudes and sad looks, or being told “*it is in God’s hands*” (Simmi). Siblings’ need for empathy, understanding, and assistance further supports the need for specific sibling-based supports such as *SuperSibs*, counselling, and peer-support groups exclusively for well-siblings.

I look forward to sharing my findings with professional, parent, community, and sibling groups where I anticipate realizing further avenues for the implication and practice of my findings. Certainly, a delightful implication for me of my finding and learning about the well-siblings' need for humour, laughter, and light-heartedness, is the understanding and knowledge that the benefits of meeting this need might also lead to long-term benefits for well-siblings. This lends strength to the act of generating fond and warm memories that one can draw on in the living of a reorganized life post cancer. My greatest hope however in terms of the implications of my study, is that well-siblings' needs will be attended to and that the message "you matter" will be translated and received by them.

Future Areas of Research

Through the experience of compiling the literature and previous research on this topic of interest, in combination with my own findings, I became aware of other potential areas of research interest. As I mentioned earlier I think it would be helpful to have a comparison group of now-adult bereaved siblings who were adolescents when their sibling had cancer and died from the cancer. Having this comparison group could provide a conversation about the different needs and experiences of well-siblings of palliative children and youth with cancer.

Another area for exploration is the unique need I found for *humour, laughter, and light-heartedness*. I am curious to further explore the ways in which attending to this need might help siblings and families in life threatening circumstances. It could be a case study listening to the voices of the well-sibling, sick-sibling, and parents. This could be an exploration into if and how this need was facilitated and met, what the outcomes thereof would look like in the immediate and long term.

Focussing specifically on the gender of well-siblings is an area of research that would create important conversations about the possible specific needs of brothers and sisters (and possibly also, different genders). Previous research has highlighted that older female siblings tend to be at greater risk of higher distress perhaps due to the gendered implications of the female caretaker role and responsibilities (Alderfer et al., 2010; McGoldrick et al., 2005, p. 156). To the best of my knowledge no research study has exclusively examined the needs of adolescent-age female well-siblings in the cancer experience. The fact that my sample was made up of only female siblings (5 older and 2 younger sisters) begins an important conversation. (As discussed in my methods section, like Pompeo [2009] who conducted a qualitative retrospective study on the experience of sisters of siblings with a disability, my intention had not been to focus solely on female siblings, rather my sample accrued this way by chance.) Future research could create a comparison study looking only at the needs of male siblings.

A further future research implication lies in the area of program development/evaluation research. In relation to my suggested implication for the creation of support groups and a camp for well-siblings exclusively, future research could add to the existing body of literature looking at sibling camp experiences (e.g., Sidhu et al., 2006). Through the design, development, pilot testing and evaluation of for example, a well-sibling-specific peer support program or camp, future research could offer further insight into the helpfulness and need for these types of supports.

In sum, I believe the findings of this study have real world application to helping support well-siblings, as well as for theory and knowledge building for researchers and clinicians (e.g., counsellors, social workers, doctors, nurses, child life specialists, teachers, etc.), and for knowledge building, practical information, support, reassurance and validation for well-siblings,

parents, and families. My hope is that by distilling and presenting the needs of well-siblings I have presented information in an accessible way that people can remember, take away, and practice.

Conclusion

My impetus to explore this area of study came from both a professional and personal perspective. Through this research process, I have a new understanding of what it is like being a sibling of someone with a life threatening illness. I am grateful to say that my insight and awareness have expanded, which will assist me in my work as a researcher, clinical counsellor, and as a sister of a well-sibling. Previous research has indicated that well-siblings are at risk for psychosocial issues (Barrera et al., 2005; Malone & Price, 2012; Woodgate, 2006), and these issues often develop as a result of one or more of their essential needs being unmet during their sick-sibling's cancer treatment (Alderfer et al., 2010; Malone & Price 2012; O'Shea et al., 2012).

The childhood cancer diagnosis has the capacity to shake a family's foundations and leave everyone scrambling for footing. Roles are altered, routines morphed and all family members are asked to adjust to a difficult new reality that may take months, or even years of hospital visits and doctor appointments, to live with in hope and uncertainty. The impact on well-siblings is often times immense. They watch as their sister or brother suffers from a cruel diseases and changes before their eyes. They witness the distress and heartbreak of their moms, dads, other siblings, extended family, friends, and caregivers. They are asked to take a supporting role, and to be flexible while the family adjusts. The journey will be complex. It will have moments of fear, love, confusion, frustration, sadness, and learning; sometimes, it will be an ebb and flow of suffering and hope. The purpose of my study was to extend the literature on the needs of well-siblings by focusing specifically on adolescent well-siblings. This is an

important step. It brings information to parents, caregivers, and professionals supporting and working with the child with cancer, and raises awareness for those supporting well-siblings and for well-siblings themselves. By clarifying the needs of adolescent well-siblings and by helping to disseminate this information into the cancer community, I believe the difficult journey can be made more manageable and less detrimental for future adolescent siblings of children and youth diagnosed with and treated for cancer. Families need to know that each member is impacted differently, and that all voices are valuable. Well-siblings need to know that their voices are valid and that they matter.

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Appendix A

Recruitment Poster

	University of Victoria	Participants Needed for Research Study
<h1>Were you an adolescent when your brother or sister had cancer?</h1>		
<p>If you answered yes, I invite you to consider participating in an important research study looking at the experience of siblings of children/youth with cancer.</p>		
<p>The aim of this study is to:</p> <ul style="list-style-type: none"> • Hear the sibling's perspective of the cancer experience in their family from their adult point of view • Understand what it was like to have a brother or sister (sibling) with cancer during adolescence (11-18 years of age) • Help future siblings and families of children/youth with cancer 		
<p>You are eligible to participate if:</p> <ul style="list-style-type: none"> • You are 19 years or older • You were between the ages of 11-18 years old (adolescent) when your brother or sister had cancer • Your sibling was diagnosed with, treated for, and survived cancer • Your sibling has been cancer treatment free for 2 or more years • Your sibling is not currently in cancer treatment and/or in palliative care 		
<p>Participants involved in this study will:</p> <ul style="list-style-type: none"> • Share their stories with the researcher (Genevieve Stonebridge) in a 1-2 hour long interview 		
<p>If you are interested in participating please contact Genevieve Stonebridge (a graduate student in the counselling psychology program at the University of Victoria) for a screening interview. Interviews can be in person, over the telephone, Skype or Facetime. Recruitment taking place across North America.</p>		
<h1>EMAIL: siblings2014@gmail.com</h1>		

Appendix B

Invitation to Participate Letter



*Department of Educational Psychology
and Leadership Studies
PO Box 3010 STN CSC
Victoria British Columbia V8W 3N4 Canada
Tel 250-721-7799, Fax 250-721-6190*

Invitation to Participate Email to Potential Participants

Working Study Title: What About Me?: Retrospectively Exploring the Needs of Adolescent Siblings of Children and Youth Diagnosed with Cancer

Dear [participant's name],

Thank you so much for your interest in my study entitled "What about me?: Retrospectively Exploring the Needs of Adolescent Siblings of Children and Youth Diagnosed with Cancer." My name is Genevieve Stonebridge and I am a Counselling Psychology graduate student in the Department of Educational Psychology and Leadership Studies at the University of Victoria. I am working with my supervisor Dr. Susan Tasker, who is a faculty member in the department.

The purpose of my research is to explore the stories of adult siblings (19 years and older) who, while they were adolescents (11-18 years of age) had a sibling who was diagnosed with, treated for, and survived cancer. To participate the participant's sibling who had cancer would have completed treatment 2 years ago or longer, and not be diagnosed as terminally ill.

Through this exploration I hope to generate insight into the specific kinds of needs and concerns participants had as a result of their experience with their sibling who had cancer, and to identify questions for future studies. Through this study I aim to gain a better understanding of what helps and hinders adolescent siblings when their sibling is being treated for cancer.

Your voice and experience as a sibling is highly valuable, and I see you as the expert of your sibling experience. By sharing your experience you are contributing to research that will potentially help other siblings. My hope is to use the information from this research to recognize the needs and concerns of siblings and to improve the quality of information and support provided by professional communities to siblings and families who are going through similar circumstances that you did.

Your participation would consist of one audio-taped interview that would be approximately 1-2 hours in length. The intention of the interview would be for you to tell your story of what it was like to be you as a sibling during the cancer experience in your family. You can describe what you remember of this time, possibly discuss how your needs were and weren't met during, and any concerns you may have had.

The interviews will happen either in person or over the phone or Skype. If the interviews are in person they will be held in Victoria or Vancouver, depending upon what is most convenient for you. After the interview is over and I have transcribed our interview, I will

contact you to go over details of what you have shared and clarify that I have heard your story correctly.

Confidentiality of your story will always be upheld to the best of my ability and you can withdraw from the study at any point. In the unlikely event that you and I know each other personally my supervisor Dr. Susan Tasker will be meeting and talking with you for the interview. This study has received approval from the Human Research Ethics Office of the University of Victoria (250 472 4545 or ethics@uvic.ca).

If you have any questions or are interested in participating in this study please email me back or call me so that we can set up an interview date and time. Alternatively, you may email or call my supervisor, Dr. Susan Tasker (250 721 7827 or stasker@uvic.ca).

Thank you so much for your interest in this study. Sincerely,

Genevieve Stonebridge, Masters in Counselling Psychology Student
Educational Psychology & Leadership Studies, University of Victoria

Appendix C

Telephone Script

The following is an example of the script to be used when participants (P) initiate contact with the primary investigator, Genevieve Stonebridge (GS); exact wording and order may change slightly depending on participants' responses:

GS: "Thank you for taking the time to call. We will need 10 to 15 minutes to talk about the study. Do you have the time to talk right now or should I call you back at a different time?"

P: "Yes, we can talk now." ("No, I don't have 15 minutes right now.")

GS: "First, would it be alright if I ask you a few questions?" ("When would be a good time for me to call you back?")

P: "Yes." ("Can you call me in 30 minutes?")

GS: "To begin I need to clarify some of the details of your experience to see that you are able to partake in my research. Are you proficient in reading and writing in English?"

P: "Yes." ("No.")

→: If YES, continue as follows. If NO, thank them for their interest and explain that the study will involve them filling out a brief demographic questionnaire as well as consent forms that will require them to be able to read and write in English.

GS: "Are you over 18 years of age?"

P: "Yes." ("No")

→: "If YES continue as follows. If NO, thank participant for their interest and explain that the study is only for people who are 18 years or older.

GS: "Were you between the ages of 11-18 when your brother or sister was diagnosed with cancer?"

P: "Yes." ("No.")

→ If YES, continue as follows. If NO, thank participant for their interest and explain that the study is only for siblings between the specified adolescent ages. If over the age of 18, such as 19 or 20 it may be possible to include the sibling in the study if they were living in the same home environment at the time of treatment and diagnosis.

GS: "How old were you?"

P: "Age"

GS: "Did your sibling survive their cancer?"

P: "Yes." ("No.")

→ If YES, continue as follows. If NO, thank participant for their interest and explain that the study is for siblings whose brother or sister survived the cancer experience. If the sibling is a bereaved sibling, I will thank them so much for being willing to share their story, and the power that being a bereaved sibling holds. I will validate them that I

appreciate their story and that it is an important one too. I will explain that for this study I am focusing solely on brothers and sisters whose sibling survived his or her cancer, and that a later study may focus solely on the bereaved siblings experience. Both point of views are valid, and for consistency with my research I needed to focus on one specific population.

GS: “Is your sibling currently in treatment for their cancer, or have they been diagnosed as terminally ill?”

P: “No.” (“Yes.”)

→ If NO, continue as follows. If YES, thank participant for their interest and explain that the study is for siblings whose brother or sister survived the cancer experience. If the sibling is a currently supporting their sister/brother through treatments of end of life care I will acknowledge their courage in telephoning me to be a part of the research. I will explain that I am looking for siblings whose brother or sister is no longer in treatment or palliative as I want to focus on what happens after recovery. I will express how I believe all stages in the cancer journey of a sibling with cancer are valid and important- and that for research consistency I needed to focus on this very specific population. I will thank them for their offer to help and wish them well.

GS: “Have you yourself ever been diagnosed with cancer?”

P: “No.” (“Yes.”)

→: If NO, continue as follows. If Yes, inform the participant that for the importance of homogeneity of all my participants I need people who have never experienced a cancer diagnosis themselves.

GS: “Thanks for sharing with me. I would be so grateful if you could participate as a sibling in my study.”

P: “Sure.” (“Actually, no thanks.”), (“Okay, thank you for your willingness this far, all the best.”)

GS: “ Wonderful. Your involvement in the study will look like us meeting at a location that is convenient in Victoria or Vancouver*. We will meet for an audio taped interview of about 1-2 hours. The intention of the interview and study is to understand what your experience as a sibling was. Learning about the experience and needs from siblings themselves will help future families dealing with a cancer diagnosis. During our interview I will ask you to share your story of being the brother and sister of a sibling with cancer. I would like to get to know what it was like to be you during this time. After the interview I will compile and transcribe your story and then email or mail you the most salient pieces I will be using in my research. The aim of this email or letter is to be sure that I have heard your story properly. At this time you can either add or remove parts, or correct information that, in your opinion, I may not have captured accurately or understood correctly... Does this sound all right with you? Do you have any questions?”

*If the participant is not located in Victoria or Vancouver, I will arrange a time to engage in a Skype interview with them. “

P: "Yes, I would like to partake." ("No. I would not like to share, I decline to be a part of your study")

→ If YES continue, if NO thank them for their time and end conversation.

GS: "Great. I would like to let you know that we are able to offer you and your sibling anonymity in the interview process should you like to partake. For example, we will use pseudonyms for both of you or just refer to you as participant and participant's sibling. For this study, it is important that you give some thought to the fact that even if no real names are used, yours and your sibling's identity could be known due to information about you or your family that could be unique. Do you have questions about this or would you like more information?"

P: "No." ("Yes.")

→: "If No continue as follows. If Yes, answer questions accordingly."

GS: Great, well if you are still interested, I would like to send you an email or mailed letter outlining the details of the study and what your participation would involve. This is called the Ethics and Informed Consent Letter. Would you like me to e-mail it to you or mail it to you?"

P: "Yes. My e-mail is _____." ("No. My address is #100 Some Street, Victoria, BC. V0A 0J0")

GS: "Thank you! Now lets set up a time and place to meet and partake in the study, does that work for you right now?"

P: "Sure." ("I need to call you back, I don't have my schedule in front of me.")

GS: Great, would you like to meet me at either an office space at UVic or your home? / I can call you back when is convenient for you?

P: "Yes."

GS: "Great can I have your address?"/ The directions for the UVic location are in the MacLaurin building office A454. The best place to park is in Lot 6 near the Phoenix building. I can send you an email map for better directions.

GS: Would it be ok if I phone you or email you the day before our interview to confirm and remind you of the study?

P: ""Yes." ("No.")

GS: Do you have any other questions for me at all?"

P: ""Yes." ("No, I think I'm fine for now.")

GS: "If anything comes up between now and when we meet, please feel free to give me a call. My cell phone number is xxx-xxx-xxxx (it's a local Victoria number) and my email is siblingstudy2014@gmail.com. Thank you for taking the time to call and talk with me. I'm looking forward to meeting with you in person. I will see you soon."

Appendix D

Ethics and Informed Consent: Part 1



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ETHICS AND INFORMED CONSENT: PART I

Working Study Title: What about me?: Retrospectively Exploring the Needs of Adolescent Siblings of Children and Youth Diagnosed with Cancer

**Principal Investigator: Genevieve Stonebridge, Masters in Counselling Psychology Student
Email: siblingstudy2014@gmail.com**

**Thesis Supervisor: Dr. Susan Tasker, Ph.D., CCC
Email: stasker@uvic.ca, Tel: 250.721.7827**

Purpose(s) and Objective(s) of the Research:

The purpose of this research is to explore the stories of adults (19 years and older) who, while they were adolescents (11-18 years of age), had a sister or brother who was diagnosed with, treated for, and survived cancer. By doing this study, I hope to learn about the concerns and needs of teenagers with brothers or sisters with cancer. This information will help us better understand and support the teenage brothers and sisters of future children and youth diagnosed with cancer.

This Research is Important because:

- This research aims to identify the needs of adolescent siblings, and what helped and what hindered them while their sibling had cancer.
- The intention of this study is to improve the level of understanding within general and professional communities of what adolescent cancer siblings' concerns and needs are.
- The information gathered will contribute to improving the quality of information and support provided to siblings and families who are living with a child who has cancer.
- The information gathered will contribute to improving the quality of information and support provided directly to siblings of children and youth living with cancer.

Participation:

- You are invited to participate in this study because you are an adult (19 years and older), who, while you were an adolescent (11-18 years of age), had a sister or brother who was diagnosed with, treated for and survived cancer.
- It is two years since your sibling was last treated for cancer, and they are not currently palliative.

- Your participation in this project is entirely voluntary and you have the right to not participate in this study. If there are any questions that are asked during the interview that you do not want to answer, you have the right to not answer them.
- You can also withdraw from the study at any point and you do not have to provide any reason for your decision.

What is Involved in Participation:

- Your participation will consist of an audio-taped interview that will last between one to two hours with me, Genevieve - the researcher. I will ask you to fill in a short questionnaire giving for example, how old you are now and how old you were when your sister or brother was diagnosed with cancer. Then we will begin the interview where I will ask you to tell me your story of being you during the time that your sister or brother had cancer.
- The interview will either be in person, over Skype or telephone. If in person, we will meet at a time and place convenient for you, either here in Victoria or Vancouver. In Victoria, the best place to meet will likely be in Dr. Susan Tasker's research office #A454 at the University of Victoria, in the MacLaurin building.
- A few weeks after the interview I will email you some follow-up questions regarding our interview to make sure that I understood your story accurately. This is a process called *member checking*, which allows you the opportunity to make sure I have captured your story correctly.

Inconvenience:

- It may be inconvenient for you to answer my email questions after our interview today.

Benefits:

- The information and experiences you share will help to improve support for future teenage brothers and sisters of children with cancer.
- Sharing your story may feel good to have someone who wants to understand what it was like to be you during the time of your sister's or brother's illness.

In another research study done by a Dr. DiGallo in 2003 with sisters and brothers, participants said that telling their stories helped them to feel better about their experiences. I hope that by participating in this study you will also have a positive experience sharing your story and perhaps develop a deeper understanding of your own experience of what it was like to have a sister or brother with cancer.

Risks:

- Of course there is the possibility that you will feel or get upset when you tell me your story. If you feel uncomfortable or wish to stop the interview at any time, please let me know. I will let you decide what you want to do next. You might want to have a little break which will be fine, or you might want to stop altogether, which will also be fine.
- If you need it, I will also have contact information for local counsellors should you wish to talk more about any stories or memories brought up during your interview with me.

Researcher's Relationship with Participants:

- It is highly unlikely that you and I know each other. In the unlikely case that we do know one another, then my supervisor Dr. Susan Tasker will be meeting and talking with you for the interview.

Withdrawal of Participation:

- You may withdraw at any time without explaining. There will be no consequences.
- Should you withdraw, your information will only be used if you give your permission. If you do not want your information to be used then your interview tape will be deleted and all my notes will be destroyed.

Continued or On-going Consent:

- As you read earlier in the section “What is Involved” I will email you when I am working with the information to check with you that I have understood your story correctly and to ask you if you agree or disagree with the overall findings from the study. The purpose of this is to see if the study participants think that the findings of the study are a good reflection of what the needs and concerns are of teenagers with sisters or brothers with cancer. If you would prefer to talk to me and if it is possible, I will meet with you in person or over the telephone to discuss your thoughts about the findings in more detail.

Anonymity and Confidentiality:

- The information you share with me (or Dr. Tasker) will be kept private, and confidential.
- No names will be given in the final research report unless you would like your name to be used. Otherwise, you can choose a pseudonym so that you can maintain anonymity (permission asked at end of consent form).
- Your sister or brother’s name will not be used in the final research report or any format when the study is presented or discussed.
- All information collected will be stored in a locked cabinet in Dr. Tasker’s research office in MacLaurin Building at UVic room #A454 and on the researcher’s password protected computer.
- All information will be kept for a maximum of 5 and will be destroyed when all data analysis is complete..

Exceptions to Confidentiality

- If you disclose about past or present child abuse I have a duty to report any potential harm to a person under the age of 19. Should you reveal any information to suggest this may be the case, I will have to report the circumstances and the names of persons involved to appropriate authorities.
- **If you have been identified or referred to the study by a person outside of the study team, they will know that you might be participating in the study. In other words, your participation will not be completely confidential.**
- I, Genevieve Stonebridge and my supervisor Dr. Susan Tasker may have access to confidential information and we will follow the ethical standards that our governing professional body, the Counselling Psychology program, and University of Victoria demand from us to maintain confidentiality.

Research Results will [may] be Used/Disseminated in the Following Ways:

If NO, I understand the researcher will change my personal identifying information to my chosen pseudonym, along with my sibling and family's information in her reporting of the results. I also am aware that it could still be possible for these individuals to be recognizable due to the unique circumstances that could make the family identifiable.

_____ (Participant to provide initials)

IF NO, I agree to have my responses attributed to the same pseudonym in the findings.

____Yes ____No

I want to remain anonymous in the findings of the study.

____Yes ____No

I want my responses presented anonymously in the findings.

____Yes ____No

_____ (Participant to provide initials)

Future Use of Data *PLEASE SELECT STATEMENT*

I agree to the use of my audio-recorded interview data for secondary analysis in future research by Genevieve Stonebridge: ____Yes ____No

_____ (Participant to provide initials)

I agree to be contacted in the event my data is requested for future research: ____Yes ____No

_____ (Participant to provide initials)

Appendix E

Informed Consent – Part II

Ethics and Informed Consent – Part II – Email script for Skype Participants

Dear (name of participant),

Thank you for your interest in participating in my study. In order to go forward with the study I need to receive your consent to begin our interview.

Attached to this email you will find a file entitled *informed consent form*. With in-person interviews I have participants sign this form after we have gone over it together. As you and I are not meeting in person I cannot receive your written consent on this form. However, after we go over the details of informed consent together and you agree to the details of informed consent you can give your consent via email. If after we go over the details of informed consent and you do not want to proceed with the interview then you do not need to reply to this.

By acknowledging receipt of this email with the word “ACCEPTED”, YOUR FREE AND INFORMED CONSENT IS IMPLIED and indicates that you understand the conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers. *Please retain a copy of this email and the attachment for your reference.*

Thank you,
Genevieve Stonebridge

Appendix F

Demographic Questionnaire

Date: _____

PARTICIPANT DEMOGRAPHIC INFORMATION

The following questions are required to describe the individuals participating in this study as a group. Only group data will be reported. That is, no individual will be identified in any report of this study.

1. Your current age: _____ (years)
2. Your gender: _____
3. Your age at the time of your sibling's diagnosis: _____
4. Your ethnic or cultural background: _____
5. What language do you speak at home? (circle one)
 - a) English as first language
 - b) Other language as first language; please specify _____
6. Your relationship status: (please circle one)
 - a) single
 - b) steady relationship
 - c) married
 - d) common-law
 - e) divorced/separated
7. What is the highest level of education that you have completed? (circle one)
 - a) less than 7th grade
 - b) junior high school (9th grade)
 - c) partial high school (10th or 11th grade)
 - d) high school graduate
 - e) partial college (at least 1 yr. or specialized training)
 - f) standard college or university graduate
 - g) graduate professional training (MA, MSc, MD, MBA, PhD)
8. Have you ever suffered from any type of mental health or emotional wellbeing distress?
 YES _____ NO _____

Please explain:

9. Are you currently suffering from any type of mental health or emotional wellbeing distress?

YES ____ NO ____

Please explain:

10. What is the gender of your sibling who was diagnosed? _____

11. How old was your brother or sister when they were diagnosed with cancer?

AGE ____

12. Do you know what kind of cancer sibling had?

YES ____ NO ____

If yes, what kind _____

13. Do you know what type of treatment your sibling received? (e.g., chemotherapy, radiation, surgery)

YES ____ NO ____

If yes, please describe: _____

14. How long was your sibling's course of treatment? (e.g., months, years)

15. What was the family make-up/arrangement like at the time? (e.g., single parent home, living with 2 parents, divorced parents, living with grandparents, foster care, other?)

16. Do you have any other siblings?

If yes, please indicate how many brothers and sisters and their ages at time of your diagnosed sibling's illness:

17. Did your sibling and parents have to live away from you during treatment? (e.g., relocate to Vancouver to children's hospital)

YES _____ NO _____ If yes, for how long? _____

18. What is your sibling's current health status?

Should you wish to do so, please note any other comments in the space provided below:

Appendix G

Interview Script

GS: Hello again [Participant's name], if we're both comfortable and ready, let's begin. What I am interested in is to listen to your story of what it was like to be you from the time that [sibling's name] was diagnosed with cancer until s/he was well again.

To help you to get settled and to focus, I'm going to give you some time alone just to doodle and think quietly by yourself. I am going to ask you to, if you feel comfortable, brain storm and make a mind map about your experience as the brother/sister to (diagnosed siblings name).

This technique is called clustering, and it is used to help get you into the mindset of telling me your story and help your memory along as you tell your story. So I will invite you now to write in the center of this page *your name, as the adolescent brother/sister of (diagnosed sibling's name) the cancer survivor*. Great, now I am going to ask you to make a bubble around it, and from that choose some words that describe your experience as their sibling. You might choose a memory, an emotion, a time period that is particularly salient...and then just go for it creating bubbles upon bubbles, themes upon themes. The idea of this exercise is to help your memory so that as you tell me your story you have some pieces to pull from.

Okay, that's great. Now that you've got that sorted through, I'm looking forward to just listening to you telling me your story. I am going to listen very carefully and will only interrupt you if I'm not sure I'm following you correctly or if I want you to expand a little for me. For example, I might ask you to "say more about whatever"] so that I "get it". Otherwise, I'll save any questions I have until the end of your story. Does that sound okay?

When participant signals the end of his or her story, I will ask: "Thank you. Do you think that you have told me your whole story? Is there anything that you might have left out? Take your time ... see if there's anything else you think might be important for me to know or that you want me to know."

Once the participant is certain that he or she has told me the story in as much detail as he or she wants to and depending on content included in the narrative, I will draw from the following set of follow-up questions which I will ask participants to respond to in as little or as much detail as they would like to or, of course, to not respond to at all:

1. What was it like to be *you* growing up in your family before [name of sibling] was diagnosed with cancer?
2. What was it like for you when (name of sibling) was diagnosed with cancer?
3. What did you need at this time?
4. What do you remember about your sibling's illness and treatment?

5. Did you understand what your sibling's diagnosis meant?
6. How did you understand cancer?
7. How did you understand the treatments?
8. How were you thinking and feeling during all this?
9. What were you doing during all this time?
10. What was going on in your life?
11. What was your communication like with your brother/sister about their cancer?
12. What was your communication like with your parents regarding your brother/sister's cancer?
13. What about communication with other siblings or family members?
14. Did you feel like cancer was talked about openly in your family?
15. What helped you during this time?
16. What could have helped you?
17. What advice would you give to a family who has recently received a cancer diagnosis in regards to thinking about the non-diagnosed sibling's experience?
18. Is there anything else you would like to say? Do you feel like you have shared everything that you needed to? Do I have at least a little bit of an idea of what it was like to be you during that time of your life?

GS: If there is anything else, memories for example that come up in the next little while that you feel would be beneficial to the research please don't hesitate to contact me to follow up. I will be contacting you in a few weeks time to check-in with the story that I have recorded here today and to check with you to see if I have accurately captured your story. This is the process called member-checking, and it allows you to be in control of your story and let me know if I have gathered the right details about your story from you.

GS: To conclude I would like to remind you that you have shared a lot today, and some people might feel quite worn out after such an interview. Therefore, I ask you to be gentle with yourself and take some time to take good care of yourself. If you find yourself feeling overwhelmed by emotions that have come up, I want to assure you that is totally normal, and also that there are resources available to support you should you need them. I'm going to [tell participant what I'll be doing after we say goodbye]. What do you have planned for the rest of your day? Thank you so much (name of participant)!