

Seeing the Arcane in the Mundane: The Spiritual as Lived by Ill Children

by

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## Dedication Page

To my husband, John Baker:

Thank you for your ongoing love, understanding, and encouragement—and for lifting my spirits when I was struggling. Thank you for listening and helping me to express my thoughts and ideas. We had some great discussions—deep ones. Many of our conversations led to a wondering about life and happenings in the world, touching on the philosophical, the spiritual, the ethical, and the political. I regret not recording these discussions because they have been part of our growth—together.

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I love you—now and always.

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## Abstract

Children with serious illnesses experience life disruptions that are of consequence to long-term health and development. The spiritual is integral to health, yet many healthcare providers claim a lack of understanding and comfort with attending to spiritual issues in practice. This hermeneutic phenomenological inquiry explores spirituality as lived by children with cancer and cystic fibrosis and highlights the importance of spirituality in the provision of holistic child healthcare. Four children aged nine to fourteen from each illness group (six males and two females) were interviewed and asked to draw pictures, forming the primary data for interpretation. Conversations with family members were also included in the analysis as supplements to the primary data. Study findings offer insights into children's lived experiences of the spiritual. They reveal unmet spiritual needs and unique ways of living the spiritual that often went unrecognized by adults. The experiences shared were profound and deeply meaningful, revealing hidden wondering and wisdom that defies contemporary views of how children understand and deal with the complexity of living with serious illness. Findings provide more nuanced understandings of the spiritual that allow for the voices and emotions of children to be heard, revealing a sense of struggle and the need to find meaning in illness with all its disruptions and demands on time and freedom. Findings also reveal the meanings in relationships that sustained children in their efforts to live well with illness. These findings provide possibilities for viewing child health differently—a view that includes the spiritual and its implications—that can lead to a more conscious awareness, wisdom, and sensitivity in practice. Findings offer ways of engaging children in conversations about illness meanings and the spiritual that recognize the complexity in language and the need for alternate strategies to mine the depths of experiences that are often hidden. Because the spiritual does not always wait for experts to arrive, findings are relevant to all healthcare providers and caregivers of ill children. Implications for interprofessional research, education, and practice are also explored, providing possibilities for seeing, exploring, and living the spiritual in our practices of caring for ill children.

*Keywords: Spirituality, Child, Health, Interprofessional*

## List of Abbreviations Used

CF: ..... Cystic Fibrosis

IWK: ..... Izaak Walton Killam (IWK) Health Centre

K-12: ..... Kindergarten to grade 12

PEP: ..... Positive Expiratory Pressure

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## Chapter 1: Introduction

Research exploring spirituality and health in Western healthcare contexts has focussed primarily on illness situations involving adults. Children may understand and express spirituality differently than adults, however. Despite the growing body of literature and research addressing spirituality in relation to child development (e.g. Fowler, 1981, 1996; Roehlkepartain, Benson, Ebstyne King, & Wagener, 2006), education (e.g. Champagne, 2008; Hay & Nye, 2006; Hyde, 2008), and mental health and health related behaviours (Cotton, Zebracki, Rosenthal, Tsevat, & Drotar, 2006; Van Dyke, Glenwick, Cecero, & Kim, 2009), there has been very little direct study of children's spirituality in the context of physical illness (Bryant-Davis et al., 2012; Elkins & Cavendish, 2004; Kamper, Van Cleve, & Savedra, 2010; Kenny, 1999; Oman & Thoresen, 2006).

The purpose of this study was to broaden understandings of how the spiritual is lived by children with life-limiting and life-threatening illnesses. Specifically, I wanted to know what illness means to children. How do they grapple with and make sense of a life beset by illness, and how is the spiritual implicated? How is spirituality lived during illness and what might this mean?

The spiritual is an aspect of life that often remains hidden, making exploration of the topic challenging. One reason for this hiddenness is that language is sometimes inadequate to describe experiences of the spiritual. Finding appropriate language to express the spiritual might be even more difficult for children. While there are many ways of approaching this type of inquiry, I chose hermeneutic phenomenology. This methodology relies on interpretation, something that is central "to understanding all the creations of the human spirit" (Eco, 1992, p. 4).

Using this methodological approach, I provided an interpretation of how children lived the spiritual in the context of having cystic fibrosis (CF) and cancer. In depth interviews and children's drawings were used to elicit children's expressions of the spiritual and meanings of illness and were the primary data for analysis. As an interpretive qualitative methodology, hermeneutic phenomenology broadens understanding of a topic through dialogue. It situates the data, or what is sometimes referred to as "text," within a broader framework of meaning.



Meaning and understanding are created through language and are historically situated. The intent of an interpretive study is to create possibilities for understanding a phenomenon differently. Although rigid definitions are problematic because they limit possibilities for viewing the phenomenon, some frame of reference is necessary. Thus, I will begin by clarifying key terms to avoid misunderstandings. I follow with a review of the literature that explores how the spiritual relates to human development and health, why this is important in the context of childhood illness specifically, and why this is important to all those who care for children whether ill or well. Finally, I will explain how this study addresses gaps in understanding and how this could contribute to a more holistic approach to child health.

### **Clarification of Terms**

Before beginning an inquiry about spirituality it is important to clarify the terms that are most often used in explorations of the topic. Clarification of the words spirituality, faith, and religion is necessary because these terms have often been used interchangeably leading to confusion. The term spirit is rooted in the Greek word *pneuma* meaning "a blowing, a wind, blast; breeze; influence; breathed air, breath; odor, scent; spirit of a person; inspiration, a spirit, ghost." In mid-13<sup>th</sup> century English usage, spirit came to mean the "animating or vital principle in [humans] man and animals" (Harper, 2001-2013). These original understandings of the word spirit denote a sense of a force moving and unseen that gives life or animates and that is a vital principle of existence. Related terms used throughout this thesis are *spiritual* and *spirituality*. Where *spiritual* means "of or concerning the spirit" (Harper, 2001-2013), *spirituality* refers to ways of being spiritual that are unique to each individual.

The English word *faith* also originated in the mid-13<sup>th</sup> century, meaning a "duty of fulfilling one's trust," specifically in relation to a pledge or promise. Around the same time the term was appropriated in theological contexts to refer to the duty of fulfilling one's trust in relation to religious doctrine (Harper, 2001-2013). While the word faith can be used to describe one's trust in and commitment to religious doctrine, it has also been used in non-religious contexts.

In the context of childhood developmental theory, faith has been described as a universal human phenomenon that is unique to each individual. It is thought to be the

underlying process for the development of beliefs, values, and meanings that give coherence and direction to life and enable people to face and overcome life's challenges. It connects us with others in shared fidelity to something beyond ourselves that is expressed and manifested in our relationships with self, others, and the world around us (Fowler, 1981, 1996; Fowler & Dell, 2004). Secular understandings of faith as described above also seem to harmonize well with views of spirituality that will be further described on page 29 and in the next chapter.

Conversely, synonymous use of the terms spirituality and religion has been challenged and thus these terms require some differentiation. "The majority of recent research suggests that spirituality is more primal than institutional religion, and is concerned with an individual's sense of connectedness and relationality with self, others, the world or universe, and with the Transcendent" (Hyde, 2004, p. 40). While spirituality is an overarching concept that may include religious and or cultural ways of being in the world, religion is a formal means of expressing spirituality and faith that adheres to a prescribed system of beliefs, traditions, practices, rituals, values, and ways of living that gives one a tangible sense of belonging to a community with shared beliefs and commitments (Kaye & Raghavan, 2002). This distinction must be made because while there are some who would not separate religion from their spirituality, there are others who claim they are spiritual but not religious. People who claim to be spiritual but not religious may not ascribe to one set way of expressing their spirituality. This may also be true for people who claim to be religious.

Because there are multiple ways of expressing the spiritual it is important to be mindful of the language used in one's inquiry into the topic. Language can be alienating. For example, those who claim to be atheist do not believe in god. For this reason, I refrain from capitalizing "god" to indicate my understanding that god could have various meanings depending on individual beliefs. Most of all, I want to avoid assumptions that give belief in god primacy over alternative beliefs and ways of seeing and being in the world.

### **The Spiritual as Integral to Human Development and Health**

Alister Hardy (1966, 1979), a zoologist with an interest in the spiritual, claimed that spirituality is innate and is a necessary aspect of human evolution and survival.

Spirituality is not only related to one's physical and psychosocial health, it is also a matter of human development (Eaude, 2003; Fowler, 1981; Fowler & Dell, 2004; Hart, 2003; Meehan, 2002; Roehlkepartain et al., 2006). Spirituality as it relates to human development is not a step-wise or incremental process; rather it is more like an unfolding of identity and place in relation to the world (Eaude, 2003; Hart, 2003; Moriarty, 2011). Additional recognition of the importance of spirituality to human development in younger people can be found in the growing debate on how to incorporate spirituality into K-12 education curricula in the United Kingdom (e.g. Eaude, 2003, 2009; Hay & Nye, 2006; Higgins, 1999; Meehan, 2002) and Australia (e.g. de Souza, 2006; Webster, 2004, 2005).

The spiritual also seems to play a significant role in human development among children who are ill. For example, adults with cystic fibrosis claimed a commitment to the spiritual that began during childhood when "physical challenges posed questions of meaning and heightened concern about the truth and relevance of religious teachings" (Canda, 2001, p. 129). These adults "described their development over the life span in phases that are marked by significant changes impacting physical, mental, social, and spiritual aspects of life" (p. 128). These life narratives did not follow the conventional assumptions of cognitive, moral, psychosocial, and spiritual stage theories. Rather, the spiritual as it related to human development seemed to be tied to episodic illness crises that prompted reflection on the spiritual in attempts to find meaning in these experiences (Canda, 2001).

Survivors of childhood cancer also experienced psychospiritual growth in their ability to make meaning in existential uncertainty (Parry, 2003; Parry & Chesler, 2005). Those who "actively made sense of their experience . . . [were] most articulate about the current or new meaning and purpose of their lives" (p. 1066). Although these studies speak of the possibility for psychospiritual growth and transformation through meaning making in illness, the authors also recognized that many might have difficulty finding meaning in their illness experiences.

In this respect, human development and the spiritual are intertwined with experiences of serious illness. Illnesses that are life-threatening or life-limiting disrupt our taken for granted ways of being in the world and challenge us to re-evaluate purpose

and meaning in life. Children may also experience spiritual distress in response to loss of purpose and meaning related to the life-limiting nature of some chronic illnesses (Fulton & Murphy Moore, 1995). Serious illness may prompt both adults and children to contemplate the future resulting in fear and suffering that gives rise to spiritual questioning (Elkins & Cavendish, 2004; Pendleton, Cavalli, Pargament, & Nasr, 2002; Wright, 2005).

In the context of clinical nursing practice and research with families it was found that spiritual issues often arose alongside suffering (McLeod & Wright, 2001; Wright, 2005, 2008). “Stories of grief and loss, illness, and suffering are filled with spirit. This spirit is about experiences, memories, tales, reports, hopes, dreams, beliefs, and relationships” (Moules, 2006, p. 233). In an attempt to make sense of suffering and death, seriously ill children often draw on spiritual sources for comfort and explanation (Purow, Alisanski, Putnam, & Ruderman, 2011). Thus, whether we recognize it or not, the spiritual is embodied in all professional helping relationships (Canda & Furman, 2010).

### **Interprofessional Significance of Spirituality**

In the past few decades there has been growing interest in research that explores the relationship between spirituality and health. This research has led to a recognition of the importance of spirituality to coping with illness in both adults and children that crosses the disciplinary and professional boundaries of medicine (D’Souza, 2007; Koenig, 2004; Levin, 2009; Pendleton et al., 2002), social work (Canda, 2001; Canda & Furman, 2010; Hodge & Horvath, 2011; Seinfeld, 2012), psychology (Bryant-Davis et al., 2012; Ivtzan, Chan, Gardner, & Prashar, 2011; Pargament & Saunders, 2007; Roehlkepartain et al., 2006), and nursing (Kaye & Raghavan, 2002; Neuman, 2011; van Leeuwen, Tiesinga, Jochemasen, & Post, 2007; Wright, 2005). Despite growing awareness of the positive relationship between spirituality and health, many health professionals lack understanding of what constitutes the spiritual and how to maintain an openness to the spiritual in practice.

Although spiritual care is a fundamental responsibility espoused in some professional ethical codes of practice (e.g. Canadian Medical Association, 2004; Canadian Nurses Association, 2008), many health professionals in both adult and

pediatric contexts cite a lack of educational preparation to address the spiritual in practice and a sense of uncertainty that can lead to avoidance of conversations related to spiritual issues (Barnes, Plotnikoff, Fox, & Pendleton, 2000; D'Souza, 2007; Fulton & Murphy Moore, 1995; Hodge & Horvath, 2011; Kenny, 1999; Koenig, 2004; Kuuppelomaki, 2002; Magaldi-Dopman & Park-Taylor, 2010; McSherry, Kehoe, Carroll, Kang, & Rourke, 2007; Pargament & Saunders, 2007; Purow et al., 2011; Rothman, 2009).

Understanding how the spiritual is lived in the context of childhood illness could provide healthcare professionals with further guidance in this area (McLeod, 2005). How these understandings might contribute to knowledge and guidance for health professionals will be made clearer in the final chapter. However, raising questions about the assumptions of traditional developmental theories, as outlined above and in the literature review that follows, is one way to open possibilities for seeing the richness of the spiritual in children's lives and how it might relate to one's own practice.

### **The Impact of Childhood Cancer and Cystic Fibrosis**

As noted above, childhood cancer and cystic fibrosis are two illnesses that engender a sense of existential uncertainty that often leads to spiritual questioning in an attempt to make meaning in the experience (Canda, 2001; Parry, 2003; Parry & Chesler, 2005). To understand the spiritual as it shows up among children with cancer and cystic fibrosis it is important to have a sense of the impact of these illness experiences on their lives. For example, cancer is the leading disease-related cause of death among Canadian children aged one month to 14 years. Although advances in treatment have dramatically improved survival rates for children with cancer, resulting in an overall survival rate of 82%, curative treatments are often intensive and debilitating (Canadian Cancer Society/National Cancer Institute of Canada, 2008). Children living with cancer not only have to adapt to the physical suffering related to their illness and its treatment but must also contend with how these impact their everyday lives. Being in hospital, missing school and social events with friends, and changes in family routines and relationships are only some of the life-altering aspects of illness these children have to endure. While these issues may be temporary for some children, there is also a risk for illness and treatment effects to have a long-lasting impact on the physical and psychosocial health of these children (Barnes, 2006; Canadian Cancer Society/National Cancer Institute of

Canada, 2008). For this reason, it is important to understand how children cope with serious illness and capitalize on potential strengths that may off-set long-term developmental problems.

For some children and families the spiritual was found to be inseparable from the cancer experience and played a key role in coping (Purow et al., 2011; Schneider & Mannell, 2006; Woodgate & Degner, 2003). A review of the nursing literature revealed that children with cancer often have unique spiritual needs resulting from the many changes and losses incurred through the cancer experience that increases their risk for spiritual distress (Hart & Schneider, 1997). Despite reports of the importance of spirituality in children's coping with cancer, very little is known about how children with cancer live the spiritual in dealing with their everyday experiences with illness (Hendricks-Ferguson, 2008). Having a better understanding of childhood spirituality as a potential strength in coping with the effects of cancer and its treatment may enable us to support children in this area.

Children with cystic fibrosis are also faced with a life-long struggle to maintain their physical health, which cannot be separated from their psychosocial and spiritual health. From a very young age these children must adhere to a daily care regime that can often disrupt the child and family's activities of daily living. Although this illness varies in its severity and does not always necessitate hospitalizations, the treatments can be extremely intense and time consuming. Having to adhere to a demanding treatment schedule may leave children feeling different from peers and may also limit them in their ability to participate in social activities. In addition to living with the daily demands of illness, children with cystic fibrosis are also faced with the reality of a shortened lifespan. While many may live into their forties, episodic complications pose repeated threats to their lives. Finding ways to nurture the spiritual may be one way to assist these children in coping with the ongoing threats of their illness while also helping them to adapt to the life-long maintenance of their health (Pendleton et al., 2002).

### **The Call of a Hermeneutic Question**

The meaning of health originates in the notion of "being whole, sound, or well." It also finds root in the "holy" or "sacred" (Harper, 2001-2013). To be healthy or whole is to experience a balanced integration of all aspects of being, including the spiritual.

Despite its heritage, Western healthcare seems to have fallen victim to dismembering—a severing of the whole that has led to treatment that focuses on a fragmented array of body parts, disassociated minds, and lost spirits. Healthcare has been partitioned and parcelled out to the appropriate disciplines, leading caregivers to lose sight of the whole—the entire child and family, each with unique needs for support in dealing with the uncertainty and suffering that illness can bring.

As a pediatric oncology nurse, I spent 13 years caring for children and their families. While I witnessed the suffering and mourned the deaths of many of these children, I also celebrated the triumphs of many more. Looking back with new eyes, the spiritual was present in all of these experiences, although I did not always recognize it as such at the time. Nevertheless, I sensed that there was something missing in the care that was being provided. Serious illness evokes questions of a spiritual nature, yet the spiritual was seldom mentioned in our daily care. I now see how spiritual children can be, but the past still echoes with their silence.

Driven by technology and the constraints of time, there were few opportunities to have meaningful conversations with children about what was happening to them. In the standard of practice at that time, care maps and preprinted forms were used to guide and document our daily assessments and interventions. There were no prompts alerting us to the importance of the spiritual in the lives of the children and families, nor were there any guidelines to help us engage in spiritual conversations with children. Spiritual care was muted and concealed in the language and expectations of institutional healthcare practice.

After leaving bedside care for a career in nursing education, I had the chance to reflect on my practice and on the present model of healthcare as a whole. Acute care has been growing more complex in the last 25 years. New technologies create new hopes and drive treatment decisions, creating an environment where care is oriented toward treating the body, finding a cure, or prolonging a life—sometimes at the expense of its quality.

This phenomenon of treating the body without understanding the profound yet hidden impact it has on a child as a whole raises many ethical questions and relates to my concerns about how children make sense of life when faced with serious illness. These concerns also relate to my own spiritual questioning and attempts to make meaning as a

child of eight when confronted with a life-threatening illness in my own family. Given my own experiences as a child, I assumed that children of a comparable age who were dealing with threats to their own health and well-being might be prompted to ask similar spiritual questions and talk about their spiritual lives. I had no expectations of what they might tell me, I was merely curious to know what they were going through and what part spirituality might play in their experiences of illness.

A hermeneutic question arrives unbidden when we can no longer reconcile what comes to meet us as a problem. The “question presses itself on us; we can no longer avoid it and persist in our accustomed opinion” (Gadamer, 1975/2004, p. 360). After reflecting on the absence of the spiritual in the care of seriously ill children, I was compelled to shed some light on their spiritual lives—to understand what they were going through, how they made sense of illness, and in what ways the spiritual was implicated.

### **How this Study Addresses Gaps in Understanding**

There are no published studies investigating lived experiences of the spiritual in the context of childhood illness. Although some studies used qualitative methods, none used hermeneutic phenomenology, a methodology that can provide more in depth understandings of the spiritual as it shows up in the lives of children dealing with serious illness.

This is also the first study exploring ill children’s experiences of the spiritual that brings interdisciplinary understandings from the literature to bear upon the topic. Perhaps opening this cross disciplinary dialogue will foster a more collaborative approach to health, healing, and the spiritual. In these respects my study is unique, filling a gap in understanding about childhood spirituality in the context of illness. The hope is that the findings of this study will contribute to knowledge useful in policy development, education, and practice that will perhaps lead to more holistic approaches to pediatric healthcare.

I would be remiss if I neglected to say that there were some unexpected limitations to using hermeneutic phenomenology in this study. Any methodology that relies on conversation and language as a primary means of gathering data would likely face the same issues. Due to the hidden nature of the spiritual and the limits of verbal



language in describing it, some children in this study had difficulty talking about the topic, leading to data that was thin in places. This is something other researchers have struggled with as well (Coles, 1990). Because hermeneutic phenomenology reveals what is hidden in everyday experience and relies on language and interpretation to communicate meaning, there were some limits to using this methodology.

For instance, there is the ever-present danger of over-interpretation. There is a chance that as a reader you may not see the same things I did, leading to alternative interpretations of some passages. In attempts to bring forth what was hidden, I may have taken some liberties in my interpretations. This is a natural problem in any analysis of language: “[I]t would be sad indeed if fear of ‘overinterpretation’ should lead us to repress the state of wonder at the play of text and interpretation” (Eco, 1992, p. 123). What we want to do is engage with the unexpected directions of language, chiefly metaphor, in taking us further in our understanding. My principal intention has always been to listen carefully and to allow the language of the participants to encourage me to think about what they were saying, and to follow paths opened up by their language.

### **Summary**

While it is understood that holistic healthcare includes care of the body, mind, *and spirit*, spiritual care is not always provided, or is not provided consistently in all healthcare contexts. Despite understandings that spirituality is part of human development and can have a positive impact on health among both adults and children, many health professionals in adult and pediatric contexts remain uncertain about how to recognize and support the spiritual in the lives of those in their care. It is important therefore to bring the terms “spiritual” and “spirituality” into the dialogue within healthcare research, education, and practice and provide possible understandings of how it is experienced and manifested in the lives of children. By broadening understandings of the spiritual as lived among children with cancer and cystic fibrosis, I hope to provide an opening for seeing the spiritual in their lives. By opening this field of vision, I will provide a foundation for understanding that may better enable health professionals to engage ill children in dialogue about the spiritual and support this aspect of their health.

## **Chapter 2: Situating the Inquiry within the Academic Literature**

Research exploring spirituality in the context of serious childhood illnesses like cancer and cystic fibrosis (CF) is virtually non-existent. However, studies involving adult cancer survivors and those with CF offer interesting insights about spirituality in these illness contexts and are briefly described here as a segue into research that involves children directly. One of these studies was conducted by a social worker who also had CF (Canda, 2001). Using heuristic and phenomenological methods, Canda explored transpersonal themes related to transcendence in the face of disability and death. Through analysis of online discussions, autobiographical accounts, and interviews involving 16 other adults (22 to 45 years of age) with CF, Canda identified a variety of spiritual beliefs, metaphors, and experiences among participants that included encounters with miracles and transcendent others. Regardless of claims of being agnostic or of adherence or non-adherence to specific religious belief systems, all participants described how various spiritual resources contributed to well-being and resilience, even in the face of death.

Using grounded theory, reflexivity, and inductive methods, Parry (2003) conducted in depth interviews with 23 childhood cancer survivors aged 17 to 29. Participants were drawn from a larger quantitative study involving 300 participants among whom 108 agreed to be interviewed. The aim of the study was to explore the impact of uncertainty in the lives of childhood cancer survivors. Survivors were at least three years post treatment and six to ten years from diagnosis. Participants were asked about experiences of positive and negative after-effects of cancer related to physical, psychological, social, and spiritual domains. The authors claimed that uncertainty was a common theme in survivors' thoughts about their present and future lives. This uncertainty related to concerns about "relapse, recurrence, development of another cancer, their children's developing cancer, and/or infertility" (p. 233). Although uncertainty was found to be a potential source of distress, it also provided impetus for "psychospiritual growth," including "a deepened appreciation for life, greater awareness of life purpose, development of confidence and resilience, and optimism" (p. 227).

Drawing from the same pool of 108 participants, Parry and Chesler (2005) used the same methods to explore how cancer might lead to psychospiritual growth and

resilience despite the many challenging after-effects of the cancer experience. Participants included 50 adult survivors of childhood cancer aged 17 to 29 who were anywhere from one year to twenty-four years from diagnosis. Despite many reports of difficulties related to having cancer, the majority experienced many positive changes as well, such as “increased psychological maturity (65%), greater compassion and empathy (61%), new values and priorities (57%), new strengths (48%), and increased recognition of vulnerability and struggle (44%)” (p. 1061).

Findings suggest that the process of coping and meaning making in the cancer experience is connected to long-term psychospiritual growth and that resilience is a potential outcome of adapting to the trauma related to the cancer experience (Parry & Chesler, 2005). Although this study suggests that psychospiritual growth and resilience are potential outcomes related to meaning making in the cancer experience, there are many who might struggle with the meaning making process. In addition, those who have experienced psychospiritual growth and resilience through finding meaning in their illness experience are not immune to future suffering. Each new health crisis has the potential to disrupt previous meanings resulting in the need for ongoing support.

These qualitative studies provide some valuable understandings about the relationship between spirituality and childhood experiences of cancer and cystic fibrosis. All of these studies suggest that engagement with meaning making and the spiritual provides a pathway to longer-term thriving and resilience. Despite the positive potential revealed in these findings, they still remain situated in adult retrospective understandings. Children’s spiritual coping strategies differ from those of adults (Pendleton et al., 2002), especially when considering the wide range of capacities of the developing child. Without knowledge of ill children’s experiences of spirituality as lived, these studies lend limited knowledge to guide spiritual care in paediatric healthcare practice.

### **Childhood Spirituality and Physical Illness**

While the forgoing research highlights the importance of the spiritual in the lives of adult survivors of childhood cancer and those with cystic fibrosis, they do not directly address the experiences of children. With the exception of the first study described below, the research exploring the spiritual among ill children tends to use religious language and “god talk” and or methods that begin with theoretical or conceptual

grounding of the topic, as is the tradition of empirical science. Much of the research about childhood illness and spirituality is also situated in a legacy of thought that has been highly influenced by theories of knowing and religious understandings as described below.

One study that touched on the spiritual in relation to experiences of ill children was by Woodgate and Degner (2003). This was a longitudinal qualitative study guided by interpretive interactionism that used grounded theory to analyze data from interviews and participant observations. Participants were 39 families with children who had a variety of cancer diagnoses. In addition to the parents, the study included the ill children and their siblings who ranged in age from four and a half to 18 years, most of whom were Caucasian (95%). Although the intent of the study was to investigate experiences of cancer symptoms, families could not discuss these without relating them to the whole of their experience and their spirituality. This led the authors to propose a theory they termed “Keeping the Spirit Alive: The Spirit Within” that was described as the ways that families utilized relational, spiritual, and financial supports and resources to help them “get through all the rough spots” (p. 103). Characteristics of the spirit described by the authors included one’s mindset or outlook on life, a force within that enabled one to continue fighting, a passion or wonder for living that referred to meaning in life and a reason to live, and a need to feel connected to caring others.

Most of the quotes from children related to how the cancer experience was affecting their lives. Although the interview questions were not explicitly stated, children’s answers seemed to be related to how they would describe their cancer experience to someone. One boy (7<sup>1</sup>/<sub>2</sub>-year-old) stated, “Uh . . . I would tell them that I missed my friends, I hate getting the pokes . . . The pokes really hurt . . . You miss school.” A nine-year-old boy said, “It is everything!” and an 11-year-old boy said, “Having cancer is hard!” (Woodgate & Degner, 2003, p.112). Although this study included children, the range in ages was wide and it is possible that the voices of the ill children may have been overshadowed by those of older siblings and parents. Because the intent of this study was to investigate experiences related to cancer symptoms, the children were not asked specifically about their spirituality. There was no mention of the

spiritual in the quotes from children, only in those from parents. This makes it difficult to discern the voice of the child in relation to the spiritual.

In a cross sectional survey of 78 youth (13 to 21 years of age) with various cancer diagnoses, Hendricks-Ferguson (2008) measured spiritual well-being and hope at four times during the illness trajectory to determine the relationship of these domains to specific times since diagnosis. They used Paloutizian and Ellison's Spiritual Well-Being Scale, a 20 item, six-point likert scale with 10 items that measured religious well-being (RWB) and 10 that measured existential well-being (EWB). The scale used to measure hope was Hinds' Adolescent Hopefulness Scale. Although the authors did not specify questions used in each scale, they described religious well-being as referring to "one's relationship with God" while existential well-being referred to "one's sense of purpose and life satisfaction, apart from any religious reference" (p. 390). Measurements were obtained from individual children who were at various stages of the illness trajectory. Children were either in the first year of treatment or at three subsequent time intervals up to five years from the time of diagnosis. The authors reported that hope scores were high for young people at all intervals whereas spiritual well-being, which consisted of both religious and existential well-being, was higher in those who were within two years from diagnosis.

The authors claimed that youth may draw on spiritual resources such as their relationships with god and meaning making when coping with prognostic uncertainty in the early stages of illness. Although interesting and possible, the authors were exploring the domains in relation to time since diagnosis. They evaluated these domains among youth at specific periods and compared findings across the sample rather than evaluating domains among individual children over time. The study was not longitudinal. It did not capture the movement of these domains as individuals experienced them over time. It also did not take into consideration the day-to-day unpredictability of the cancer experience and the impact this may have on individual measurements.

Using a pre-defined set of questions also limits responses, perhaps missing alternative understandings of spiritual experiences and resources specific to individual children. Even prior to initiating the study, the authors acknowledged that "no single instrument is recognized as the 'gold standard' to specifically examine spiritual well-

being (SWB) or religious beliefs and practices” (Hendricks-Ferguson, 2008, p. 388). It would be very difficult to find a set of specific questions that captured the whole of one’s spiritual well-being. Spiritual well-being is not static.

Another quantitative study explored the relationship of positive and negative religious coping on the adjustment of 87 adolescents (8 to 17 years of age) during and after hospitalization for asthma (Benore, Pargament, & Pendleton, 2008). The participants were predominately African American with a Baptist background. Questions measuring positive religious coping related to one’s relationship with god and an understanding that god is a supportive presence. Questions measuring negative religious coping included questions such as “I think the Devil did this to me,” “I think God did this because I was a bad person,” and “I think God does not love me,” (p. 276). As predicted, they found that negative religious coping was related to poorer adjustment during and after hospitalization. Contrary to their predictions, positive religious coping did not result in better adjustment and was actually associated with more anxiety post hospitalization.

The authors felt that this may have been due to a delayed effect of positive religious coping or because children were in less distress post hospitalization and did not need to rely on such coping strategies (Benore, Pargament, & Pendleton, 2008). Although not stated, it is also possible that asking questions about negative religious coping may have prompted participants to think about and perhaps doubt previously held beliefs, contributing to poorer adjustment. In addition, perhaps the use of religious language was alienating for some, leading them to dismiss other possible spiritual sources of comfort and support. The authors cite many limitations to this study including those related to the sample size and composition, the reliance on child and parental self-report data, and issues of measurement. The study did have many issues with regard to measurement—some of which I state above. Because the authors were exploring religious coping, a very individual and personal experience, self-report data is required. The limitations lie more in the approach and in the framing of the topic. Limitations are also inherent in the use of religious language in questions used to explore the topic. Questions such as these may uncover some aspects of spirituality while missing others.

Using focussed ethnography, Pendleton et al. (2002) also explored the role of religiousness and spirituality in coping with illness. They interviewed 23 children (5 to

12 years of age) with cystic fibrosis along with their families. While parents were asked to fill out a questionnaire about spirituality and religiousness, the children were asked questions about illness and how they coped using prompts such as “some kids say things like religion, faith, prayer, or God” (p. 3). The children were then asked to draw a picture of themselves with god when they are sick, providing a source for expression and elaboration. Using grounded theory as a method of analysis, the researchers found that children used a combination of 11 different spiritual coping strategies that were almost always related to reports of positive health outcomes. Most spiritual strategies related to understandings and feelings of connection or disconnection with god or a religious community and related to god’s supportive role in illness and in their lives. However, for some children there was a disconnection between themselves and god, especially for those who were not overtly religious (Pendleton et al., 2002). Referring to god in the wording of questions may have been leading for some children causing them to answer affirmatively. For those who did not feel a connection to god, these questions may have stifled individual expressions of the spiritual.

Kamper et al. (2010) conducted spiritual quality of life interviews with 60 children (6 to 17 years of age) with advanced cancer. The participants were Latino (65%) and Caucasian (30%) and were recruited from four facilities in Southern California. The researchers asked the children eight questions centering on what made them happy or unhappy and what made them feel better, what they might do to make their families feel better, what they did for fun, and what they did for fun this week. The remaining questions asked children if they felt closer to god when sick or if they prayed and whether or not it made them feel better. What made children happy and made them feel better were their relationships, enjoyable activities, and being free from the constraints of illness. What made most of the children unhappy were the effects of illness and not being with friends or family and not being able to do the things they used to do.

The majority of children in Kamper et al. (2010) said they felt closer to god (78%) when they were sick and most (77%) said they prayed. Many prayers (59%) were related to getting better, whereas many others (39%) were for family, other sick children, and friends in heaven. Most children (82%) believed that praying helped. A smaller number of children thought prayer did not help and that they were ignoring or were mad

at god. Some children helped their families by hiding their feelings about illness, by staying positive, or by protecting them from emotional distress. These responses were often surprising to parents. Some parents stated that they did not know their children were feeling this way and never thought to ask their children such questions (Kamper et al., 2010).

Although the findings presented here may provide some understanding of children's spirituality when ill, some of the questions were closed ended or leading. Confining dialogue to such questions inhibits exploration of other ways children might live the spiritual. Kamper et al. (2010) admit that there are no reliable or valid measures for assessing children's spiritual concerns and state that this was a limitation of this study.

Although the few studies found provide some information about the relationship between the spiritual and coping among ill children, they did not provide the opportunity for expression that could assist in understanding the variety and richness of the spiritual as lived. Studies that used overtly religious language may have hampered children's expressions of what they experienced as spiritual. It is also possible that parental, and even sibling views, could have overshadowed the voices of ill children in some of the qualitative studies where children were interviewed alongside their families. The ways that younger children express or understand the spiritual may not be easily revealed in family interviews or survey questions. The wide age range of the children in most of these studies also limits the findings.

Research exploring spirituality among children as they are living through illness is lacking. However, there is a growing body of knowledge related to spiritual experience among healthy children. Within this literature are a few references to children who were ill or physically disabled. Situated primarily in the fields of education and psychology, this body of knowledge provides a starting point for this study. First, I provide a brief overview of the legacy of thought surrounding childhood spirituality followed by a review of seminal research on the topic. This will provide the ground for how I view the spiritual and ways of knowing that guide my exploration of the spiritual among ill children.



## **Evolution of Thought on Childhood Spirituality**

Until recently it was commonly thought that children were not capable of being spiritual. This was due in part to the way the spiritual has been viewed. Piagetian concepts of child cognition have also restricted understandings leading to assumptions that young children could not grasp the abstract and therefore could not comprehend the spiritual. Most of the spiritual experiences revealed by children in recent research dispel this naïve assumption and lay open what has been hidden, to the surprise of many adults (Hart, 2003; Robinson, 1983). What follows is an account of the discoveries made when assumptions such as these are recognized and questioned, making way for deeper understandings of how the spiritual is manifest in the lives of children who perhaps do not or cannot articulate it in ways that conform to popular conceptions of the phenomenon and theories of knowing.

Between 1972 and 1981, a Christian minister and educator by the name of James Fowler (1981) conducted an interpretive study to uncover deeper understandings of spirituality across the lifespan. He analyzed 359 conversational interviews and observations with people ranging in age from three and a half to 84 years and proposed a theory of faith development that suggested that children were quite capable of having a spiritual life. His research was thorough and systematic—revealing patterns and common meanings among people disparate in age and belief systems. He also drew on the writings of scholars of theology and developmental psychology. Although Fowler’s work offers many valuable insights about the way children experience the spiritual, his application of cognitive, psychosocial, and moral developmental theories in the analysis, provides a view of childhood spirituality that is less developed and becomes more sophisticated as a person reaches adulthood.

These views of childhood spirituality and ways of knowing were soon questioned by others. In a large scale study initiated in 1969 by zoologist Alister Hardy (founder of the Religious Experience Research Centre), public advertisements were sent to an indeterminate number of adults to elicit detailed accounts of spiritual experiences (Hardy, 1966, 1979). There were no criteria for inclusion. Hardy was casting a wide net, hoping to gather as many diverse accounts as possible. Hardy’s request was for a written account, including feelings and their effects, of any experience of being “conscious of,

and perhaps influenced by, some such power, whether they call it the power of God or not” (Hardy, 1979, p. 18). Of over four thousand responses, about 15% claimed their most memorable spiritual experiences occurred during childhood, even though they may not have had the language to describe it as spiritual at the time.

This surprising and intriguing finding prompted Edward Robinson (1983) to explore this phenomenon further. By reconnecting with these respondents, Robinson asked more nuanced questions in order to flesh out the particularities of these experiences. Of the 362 respondents in Robinson’s study, 10% reported having spiritual experiences before the age of five. Many more reported having spiritual experiences between the ages of five and 15 (70%), and the remainder said their spiritual experiences happened after the age of 15.

In his interpretive analysis of these narratives, Robinson (1983) concluded that children may have a greater capacity for spiritual awareness and experience than adults. This claim is predicated on respondents’ claims of having their spiritual experiences dismissed by adults who felt that these experiences were irrational. These experiences did not conform to logical thought—thought that seems to replace openness to mystery sensing as children are acculturated into socially acceptable and more adult ways of thinking (Robinson, 1983).

The childhood experiences Robinson (1983) described are varied and particular to each respondent yet share qualities that they all deemed spiritual. Some of these experiences were described as feelings of being part of something outside oneself, of being at one with nature, a sense of unity of all things, experiences of extreme beauty and perfection, an energy that flowed through them, or visions of intense light and color. Accompanying these experiences was a sense of knowing that defied logic and a certainty that required no proof from outside sources. In addition, Robinson recognized that these experiences were vividly remembered years later indicating their profundity. While all respondents claimed that these childhood experiences were significant, the majority felt that the growth of understanding of these experiences and subsequent experiences in adulthood added to the significance of these early encounters with the spiritual. Robinson claimed that this may have been due to the growing capacity to articulate meanings through reflection on these early experiences.

Another interesting finding of this study was that these spiritual experiences were often unvoiced (Robinson, 1983). Reasons cited for this silence included the unavailability of appropriate language to describe these experiences and the dismissal of the legitimacy of these revelations by adults whose reliance on logical thought can preclude validation of children's experiential knowing (Adams, 2012; Hay & Nye, 2006; Nye, 2009; Robinson, 1983; Scott, 2004; Sexson, 2004). Scheindlin (2003) proposed that society's lack of support for emotionality and embodied knowing may lead children to doubt their own intense emotional feelings as part of their spiritual experiences. This doubting of experiential knowing may even lead children to harbour feelings of inferiority and incompetence (Lester, 1985; Smith & McSherry, 2004), perhaps contributing to silence.

More recent research such as Tobin Hart's (2003) hermeneutic analysis of in depth interviews and written accounts from hundreds of preadolescent children and adults also reveals that spiritual experience in childhood may be more common than previously thought. He described five general kinds of spiritual capacities of the child—wisdom, wonder, wondering, the meeting between you and me, and seeing the invisible. Hart's drew his data from descriptions of spiritual experiences provided by ordinary people and from autobiographical accounts describing spiritual experiences of famous poets, scientists, and spiritual leaders. Of these responses and literary accounts, only one person reported having a chronic illness. This person was an 11-year-old boy who had multiple sclerosis who had already experienced the death of his three older siblings from the same disease. Hart described this boy as having profound wisdom, a love of writing poetry, and a "single-minded mission to 'spread peace in the world'" (p. 27). With regard to his illness, this child admitted to being sad about it sometimes but seemed to accept it as part of god's plan.

Daniel Scott's (2004) hermeneutic analysis of 22 retrospective adult narratives of spiritual experiences in childhood provide similar findings to Hart's, although they are articulated differently. Scott described qualities of childhood spiritual experiences as something beyond them or within them that acted on their lives, a sense of unity, oneness, or connectedness to life, a feeling of love from a transcendent other, knowledge or insight beyond what is expected, or intense feelings that resulted in heightened

awareness. Most of these spiritual experiences were also associated with a variety of emotions, and for some the experience became emotionally charged in relation to negative responses to the sharing of their experiences with others. A few respondents also reported that these experiences were life shaping, contributing to their spiritual identity and life direction. Similar to findings by Robinson, both Hart and Scott describe rich and diverse spiritual experiences that often remained private, perhaps due to unavailable language to describe them or to feelings that these experiences did not fit with the dominant culture's reliance on logical and rational thought.

Robert Coles (1990), a psychiatrist and researcher, has offered very compelling and in depth views of children's spiritual experiences. These experiences were drawn from many years of prolonged engagement with children (primarily between 8 and 12 years of age, with a few as young as 6 and as old as 13) from various geographical, political, and religious contexts. Using methods he described as phenomenological and existential, he provided descriptive accounts of children's spiritual lives drawn from conversational interviews and children's artwork. He presented his findings as stories that reveal the candid insights and wonderings of children without recursive definitions or theorizing. He found that all children were quite spiritually aware whether they were religious or not. Their spirituality seemed to be manifested in their connectedness to others and the earth and in a sense of purpose and direction in life. He illuminated the diversity and complexity of children's spiritual experiences and how these understandings influenced their adaptation to crisis and understandings of how to live a good life, which seemed to be highly influenced by their diverse religious and cultural contexts.

Among the children Coles (1990) interviewed, a few were living with life-threatening or life-limiting illnesses. In the course of interviewing a group of Jewish children, one of them—a ten-year-old girl named Leah—was diagnosed with leukemia. Bringing the children together once again, this time without Leah, Coles witnessed how these devoutly religious children began to question god. They did so with incredulity. They could not fathom how god could allow such a thing as illness. Waiting for them to offer some answers to such a weighty question, one of Leah's friends referred to the story of Job. She questioned why it was wrong to long for relief of suffering and that perhaps a

cure *would* be found. Meanwhile, Leah in her hospital bed drew comfort from her family, her faith, and the bible—especially the psalms. She did not question god as the others did and in Coles’ words “she wanted Him addressed with reverence and affection and trust rather than from the vantage point of the vulnerable and enraged beggar” (Coles, 1990, p. 275). Even in her death Leah found strength in her faith as evidenced in her last words. “I’d like to go to that ‘high rock’” (p. 276) she said, referring to the place where Moses talked to god.

While many of the children in Coles’ study were devoutly religious, many still had questions and pondered the mysteries of their religious teachings. Among those mysteries were those of suffering that were sometimes accompanied by questions of fairness such as those pondered by Leah’s friends. Another poignant example of this spiritual pondering can be found in Coles’ (1990) exposé of an 11-year-old boy from a Catholic household who shared his innermost thoughts and feelings about living in an iron lung as he contemplated his uncertain future recovery from a severe form of polio. From this boy’s profound pondering on god, life, and world, evidence of his adherence to the concept of reciprocal fairness and immanent justice can be found in his composing of his world and in finding meaning in his illness. For this boy, in attempting to answer the question of why he was ill he ruminated about his past infractions of perceived moral rules and considered these to be possible reasons for his present condition. From these ponderings it can be seen that one’s beliefs about purpose and meaning in illness and suffering relate very much to the spiritual—even for children.

Leola was another child from Coles’ (1990) study who knew suffering (aged 9). After becoming a paraplegic in a car accident that claimed her father’s life, Leola found strength in her connectedness to god through prayer. Preferring to kneel as she prayed she often struggled to pull herself up from the floor into a kneeling position by her bed. She described her experiences of becoming lost in prayer where god came and took her. In this state she was no longer thinking or talking but was somewhere else—outside herself—looking down on “poor little me, Leola” (Coles, 1990, p. 201). She prayed for her legs and sometimes talked to them. She would tell them how sorry she was that this happened to them and that she would not forget them [as though they were dead to her], assuring them that her arms would “take up the slack” (p. 201). She imagined that if she

met Jesus he might fix her yet voiced contented acceptance if he did not, exclaiming that it was the soul that was the most important.

The spiritual lives of children were just as rich among those who claimed not to be religious. Eric, a 12-year-old proclaimed agnostic acknowledged that there is too much fighting and death because of religion and reminded Coles (1990) that this still goes on today. He did not deny the value and truth in various religious teachings but abhorred the divisiveness that comes from righteousness and certainty that proclaims one's beliefs to be the only way or somehow better than another's. Eric also contemplated the big questions in life, such as how did the earth come to be. He admitted finding no answers, only more questions. Prompted by the tragic death of a friend, Eric also pondered the mystery of death with the knowledge that we will all die one day. He questioned the unfairness of his friend's death and others' religious explanations that it was god's will, to which he replied, "I can't buy that, all that!" (p. 284). This led back to a family story that rooted him in his living with messages about being grateful and about being a good person and accepting death and uncertainty as a part of life.

Sylvia, a girl of 11 years also contemplated the unfairness of life. Witnessing her brother's struggle with cystic fibrosis, knowing of his suffering and eventual premature death, she wondered why god had not answered her prayers. Yet when she heard her brother's gratitude for the beauty of the ocean and the sand during a day at the beach she realized she should be more like him. Although this helped to ground her in her living, she continued to ask many spiritual questions, only to be left with even more questions. Refusing to resort to religious understandings, she "expect[ed] no miracles" and said you "have to settle for what you've got" (Coles, 1990, p. 298). Her friend Norman, who was 12, responded to her statement with an sophisticated and profound rejoinder—one that is better read than described here.

The rich and deeply meaningful experiences described by the authors above reinforce understandings that childhood spirituality is incredibly diverse and is not wholly dependent on developmental capacities of knowing. While Fowler (1981) described the capacity for spiritual knowing among children based on cognitive capacities, he also recognized the importance of bodily knowing in spiritual development. It is the experiencing of the world relationally through our bodies that

provides the basis for knowing the world (Merleau-Ponty, 1962/2002). This concept of embodiment becomes especially salient for ill children because illness and its treatment may result in changes to the body that are sometimes intolerable, leading to physical, psychosocial, as well as spiritual suffering.

### **Ways of Knowing the Spiritual**

Embodied knowing is what some might consider part of a “sensing-awareness” (Hay & Nye, 2006) that often defies our efforts to describe it. It is an ontological awareness of the “here and now” in which our entire being becomes integrated with our surroundings and the objects or subjects of our focus. This is one of the modes of being that Hay and Nye, and Hyde (2008) recommend we begin to look for the spiritual in children’s everyday experiences. In fact, this was one of the sensitizing concepts Hay and Nye developed from findings from a pilot study and previous research. It was a means of structuring their approach to avoid religious language when exploring children’s spirituality. Other sensitizing concepts used were “mystery-sensing” and “value-sensing.” Mystery-sensing was another concept that helped the researchers tap into the transcendent dimension by attending to children’s sense of wonder, awe, and imagination. Value-sensing accounted for the aesthetic and emotional dimension that revealed the importance and meaning of events in children’s lives.

Using these sensitizing concepts, Rebecca Nye (Hay & Nye, 2006) explored childhood spirituality using individual interviews with 38 children from two secular schools in Britain. Interviews with an equal number of boys and girls aged six to seven (18) and 10 to 11 (20) were the primary source of data. The participants were predominantly Caucasian (all but one) and most were not affiliated with any formal religion (28). Of those who did identify with formal religion, four were Muslim and the rest were of various Christian denominations. Using prompts such as story and pictures, Nye explored spirituality using the sensitizing concepts to guide the three separate half-hour interviews with each child.

Using grounded theory, Hay and Nye (2006) found that each child had a particular spiritual style they called the “signature” phenomenon that was not necessarily dependent on age, gender, class, or religious affiliation. The signature phenomenon was a concise way of summing up each child’s way of expressing the spiritual that was unique

to each. Hay and Nye did not give all 38 examples but provided two examples along with descriptions. The two examples given were those of a six-year-old girl (Ruth) and ten-year-old boy (Tim). Ruth's spirituality seemed to manifest in an "aesthetic appreciation of the natural world" (p. 95). Tim's spirituality, on the other hand, seemed to center around an "inner struggle" (p. 96). While each child had individual ways of experiencing the spiritual, Hay and Nye noticed that as an older child, Tim seemed to be able to reflect more intentionally on his spiritual experiences, thoughts, and feelings whereas Ruth experienced her spirituality just as intensely but perhaps more directly.

Hay and Nye (2006) found many examples of their sensitizing concepts in children's actions and responses but at times found it difficult to draw out children's spiritual experience using these concepts. Another surprising finding in this study was that despite most children's lack of knowledge and affiliation with religion, they often turned to religious language as a way of making sense of a situation or as a way of explaining how seemingly ordinary experiences were spiritual. For example, Katie, a six-year-old child from a secular background who had never been to church often referred to god when trying to fathom the mysteries of life. When discussing a picture of a starry sky, she commented that only god could reach that high. When talking about knowledge, she stated that god knows everything and that her knowledge of good and bad was god-given. Katie also accepted that there are some things that are beyond human understanding that she said that only god could know, such as how "we get alive" (p. 102). Even when turning to religious language, children were often reluctant to stay with this language, sometimes because it seemed unacceptable or embarrassing within the dominant secular discourse (even within religious families) or it was inadequate in describing their experiences.

The overarching theme Hay and Nye (2006) used to capture the whole of their findings was "relational consciousness." Although they presented this within a constellation of contexts, conditions, strategies, processes, and consequences, they also questioned if this way of categorizing contradicted their initial effort to refrain from parsing and closing the topic down. In order to simplify the understanding of relational consciousness, they described it as children's relational awareness with self and between self and other people, the world, and a transcendent other.



Hyde's (2008) research also used Hay and Nye's (2006) sensitizing concepts to explore the spiritual lives of children. Brendan Hyde is an Australian educator and researcher with particular interest in religious and spiritual education. Hyde used hermeneutic phenomenology to explore spiritual experiences of groups of children in grades three and five, each from three separate Catholic Schools. Each group consisted of both boys and girls totalling 35 children in all. Three videotaped interviews per group, coupled with activities and observation (one half hour to one hour each), were the "text" used for interpretation. Characteristics of spirituality that were identified consisted of what Hyde called the felt sense, integrating awareness, weaving threads of meaning, and spiritual questing. He also identified some factors that may inhibit children's spirituality.

The felt sense was understood as the experience of being caught up in the immediacy of an activity in which children drew on wisdom of the body (Hyde, 2008) similar to Hay and Nye's (2006) sensing-awareness. Integrating awareness was described as what happened when the children became absorbed in a common activity that seemed to provide a safe and inviting space that allowed for the emergence of another level of awareness and interaction. This interaction appeared as flow in which the activity became pre-reflective and conversation emerged often with a forgetfulness of being observed. It was a fusing of relation, time, space, and action that seemed to unify these aspects of experience as a whole. Weaving the threads of meaning entailed children's use of a sense of wonder in which they drew on eclectic frameworks of meaning in order to make sense of events, develop a view of the world, and make meaningful connections with self, others, world, and sometimes a transcendent other. Spiritual questing was understood as the way children looked for more authentic ways of connecting that seemed to appear in children's relationships with a transcendent other and with family, in their interest in the supernatural, in acts of altruism, and in contemplating the big questions of life (Hyde, 2008).

In order to understand the spirituality of preschoolers aged three to six, Champagne (2003) spent time observing groups of Canadian children in three different day care centers while engaged in everyday activities. She realized that it would be difficult to adapt in depth interview questions to their language abilities and chose to observe their "being" as they naturally engaged with the world. She used hermeneutics to

analyze the data and found that these children exhibited three modes of being—the sensitive mode, the relational mode, and the existential mode.

Moriarty (2011) also used hermeneutic phenomenology to explore children’s spirituality using the concepts of consciousness, relationality, and a complex set of dimensions—roadmap, identity, and worldview. Data was drawn from semi-structured interviews with 24 children aged eight to ten years. He applied Champagne’s spiritual modes of being to develop a spiritual profile on each child. Findings described how children reached beyond themselves for connectedness with others (reaching beyond the self), including a transcendent other, how they searched within themselves and connected to self (reaching within the self), how the environment influenced their values (charting a path), and how children’s identities were shaped by these experiences (footprints).

While these studies offer various approaches to exploring the spiritual among children, I chose not to impose such constructs on the collection or analysis of data. Alister Hardy (1979) said it best when looking for a way to elicit written descriptions of spiritual experiences from adults. He remarked that “the specimens we are hunting are shy and delicate ones which we want to secure in as natural a condition as possible; we must at all costs avoid damaging or distorting them by trying to trap them within an artificial framework” (p. 21).

### **Ways of Studying the Spiritual**

In the foregoing review of research exploring childhood spiritual experience (primarily in contexts other than illness), hermeneutics and phenomenology were the approaches most often used, either singularly or in combination. Hermeneutic phenomenology is an approach to exploring lived experience that extends understanding through dialogue, uncovering deeper meaning through language, art, and symbol. As applied in some of the research described above, this approach provides more nuanced understandings of the spiritual as lived. Using hermeneutic phenomenology as a research approach entails interpretation that allows for movement in understanding through dialogue. Hermeneutics enables a depth of analysis that will shed more light on the particularities of children’s spiritual experiences. Using hermeneutic phenomenology in the exploration of spirituality among *ill* children specifically will extend the limits of

present understandings by revealing the complexity, diversity, and fluidity of the spiritual as it is lived.

Of the above studies that address spirituality among preadolescent and young children, some are retrospective accounts from adult perspectives that miss the nuances of how the spiritual might be experienced and expressed by children *as lived*. Although some of these studies investigate children's spirituality in the context of crisis (e.g. Coles), the majority explore the phenomenon as it appears among ordinary school children with an interest in how to apply findings to spiritual education. Interestingly, the commonalities among the findings relate to ways of knowing and being that are aesthetic, embodied, relational, and sensitive to a transcendent awareness. They also suggest a quality of connectedness with self, other, world, and the transcendent as well as how children find purpose and meaning in life. These are the understandings that provide the grounding for my view of the spiritual that guides this study.

### **A View of the Spiritual**

While some contend that it is counterintuitive to attempt to define the complex, multidimensional phenomenon termed spirituality (Eaude, 2003; McCarroll, O'Connor, & Meakes, 2005; Scott, 2006), without a frame of reference to guide one's inquiry, exploration of any phenomenon remains difficult, if not impossible. To define spirituality however is to express it in language—to apply words that lay claim to what it is. Using language that confines one's view of the spiritual may deny possibilities for understanding that lie outside recursive definitions. Once spirituality is defined, it becomes more object than a lived experience, a step that could be distorting. Scott (2006) describes a similar struggle—concerned that in defining spirituality in order to study it, it becomes deflated, lifeless, and perhaps even dangerous. By confining the spiritual to lifeless language it is unable to move and flow and becomes an object of inquiry rather than a way of being that we seek to understand.

When the spiritual is manipulated this way, especially in the course of research, there are dangers inherent in what might be done with such findings. An example of this can be found in application of developmental conceptions of childhood spirituality and ways of knowing as described previously. Subsequent research has found that in applying these developmental theories, researchers and others underestimated the

capacities of children and missed some very important aspects of their spiritual lives. By defining the spiritual using overtly religious language, we may also alienate some children and fail to capture aspects of the spiritual that are not connected to religion. If we then use findings from research that defines spirituality in these ways to inform practice, there is the potential to do great damage. Thus while it is necessary to define spirituality to some degree in order to frame one's approach to inquiry into the topic, it is important to take caution in doing so.

In the midst of this conundrum, I offer a more tentative and partial description of spirituality—one to guide the study, rather than a definition per se. For the purpose of this study the spiritual is understood as embedded in life and is manifested in who we are, how we view self, other, and world, and how this is enacted in our everyday living. Spirituality is lived in our commitments to what we hold dear and in the process of finding meaning and purpose in our lives. It shows up in our relationships with ourselves and all that is “other,” wherein “other” includes other people and objects, the environment, and the systems and institutions with which we engage. The notion of “other” also consists of the transcendent, or that which is beyond the physical or material. For the sake of clarity, I will elaborate on meanings given to the word transcendent as it relates to spirituality. The reason for doing so is grounded in ontology and the need to recognize the importance of the intangible in the formation of spiritual knowing.

### **Transcendence as it Relates to Spiritual Knowing**

Transcendence has been described as one's ability to move beyond the limitations of physical existence. Transcendence may also be the experience of overcoming crisis with integrity and wholeness and a renewed view of self and of the situation that provides greater understanding, meaning, and purpose (Canda, 2001; Chiu, Emblen, Van Hofwegen, Sawatzky, & Meyerhoff, 2004; Kaye & Raghavan, 2002). Interestingly, this notion of transcendence seems to be closely related to understandings of resilience that are described in a growing body of international literature that reveals the capacity of young people to rise above adversity and crisis where they not only survive but *thrive* (Ungar, 2005). These understandings may be useful when exploring children's experiences with cancer and cystic fibrosis because they speak of the possibilities of thriving and a return to wholeness in the midst of serious illness.

Transcendence has also been described as one's ability to move beyond the self in order to identify with another in *their* experience (McCarroll et al., 2005). Taken to another level, this might be understood as what is needed for us to be able to be present, engaged, and compassionate when bearing witness to another human being's suffering. It also speaks to the child's ability to identify with others and to show compassion.

Although some developmental theorists claim that young children can be egocentric, accounts of children's understanding and compassion for others have been detailed in the words and actions of many children (Coles, 1967, 1986, 1990, 1997; Hart, 2003) with some being as young as seven months of age (Hamelin, Wynn, & Bloom, 2007; Kimes Myers, 1997; Warneken & Tomasello, 2009). *Affect attunement* (Stern, 1985), which is the infant's capacity to experience the felt emotions of closely related others also gives credence to our innate ability as human beings to transcend ourselves and identify with the feelings and experiences of others.

In the original 1985 version of *The Interpersonal World of the Infant: A View from psychoanalysis and developmental psychology*, Stern used a variety of experimental methods while observing and interpreting mother-infant dyads interacting in a variety of situations. In the "Introduction to the Paperback Edition," Stern explains how his understandings have changed since writing the first edition based on dialogue with other thinkers in the area of psychoanalytic and developmental psychology. He attends to the voice of his critics but maintains a knowing of the subject matter with ideas that are innovative and insightful. The fundamental principles he speaks of, as ways of being in relation, seem to dovetail with thoughts of Alister Hardy (1966) and others as noted above. Although there are still some dualistic undertones in his verbiage, he offers some compelling evidence for primal, non-verbal ways of knowing, being, and relating.<sup>1</sup>

Stern differentiates between affect attunement and empathy in that affect attunement is an unconscious process in which affective feelings are not mentally processed as being separate from the person. It is what one might experience as a feeling of being "at one" with another. Although Stern's research speaks from a dualistic view of subject object relations, the findings appear to be in harmony with understandings of

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<sup>1</sup> See Stern, D. N. (2006). *The interpersonal world of the infant: A view from psychoanalysis and developmental psychology*. New York, NY: Basic Books.

transcendence as “surmounting,” “climbing over,” and “going beyond” (Harper, 2001-2013) subject-object distinctions. Transcendence is worth consideration when exploring spirituality with ill children because it describes a quality of connectedness that goes beyond the superficial and mundane.

Some claim that it is in our nature to search for experiences that emulate feelings such as transcendence and that spirituality is a journey that seeks “ultimate unity” (de Souza, 2006) between self and all that is other. Perhaps this longing is rooted in our early experiences of “at oneness” with self, other, and world that motivates us in our search for the spiritual throughout life. Some even claim that this search for eudemonia or “good spirit” or “happiness” (Harper, 2001-2013) might lead some people to engage in behaviors such as drug or alcohol use, extreme sport, or death defying stunts that emulate feelings of transcendence (Bussing, Foller-Mancini, Gidley, & Heusser, 2010). This may also explain in part why spirituality as an alternative might act as a protective factor against such risk behaviors among youth (Kim & Esquivel, 2011) and has been found to be related to children’s feelings of happiness and well-being (Eaude, 2009; Holder, Coleman, & Wallace, 2010; Rowold, 2011).

Understandings of a transcendent other are also important to consider. In the Western world (and perhaps everywhere) most children of school age have at least heard of god and, despite their belief, disbelief, or doubt in god, it is likely that they have given god some private thought and an imagined form (Fowler, 1981; Laurin, Kay, & Fitzsimons, 2012; Rizzuto, 1979). One’s attitudes toward god, if one believes, have important implications for meaning making in life. For children who grow up in a monotheistic tradition, understandings of god may also have important implications for understanding meaning and purpose in illness (Canda, 2001; Kushner, 1981; Wright, 2008). Examples of this phenomenon among children have been described previously in the research conducted by Coles (1990), Hart (2003), and Robinson (1983).

### **Story as a Means of Articulating the Spiritual**

An exploration of preadolescent children’s spiritual dreams revealed that although the children did not express their experiences for fear of being ridiculed by peers or of being dismissed by adults, they demonstrated a great need to share these experiences with others (Adams, 2001). This need for belonging and to be accepted,

listened to, and understood by others is fundamental to providing spiritual care to children of this age (Adams, 2012; Lester, 1985). Children often show interest in metaphysical and spiritual questions and issues and have reported that spirituality is an important part of life and is linked to well-being (Bosacki & Ota, 2000; Cotton et al., 2006; Gersch, Dowling, Panagiotaki, & Potton, 2008). It is imperative therefore to give children voice and to allow them to share their personal and private spiritual experiences with others, if and how they choose.

Experiences of the spiritual are sometimes difficult to articulate for adults, let alone children. One of Hay and Nye's (2006) suggestions is to attend to children's "mystery-sensing" as an avenue for exploring these aspects of the spiritual with the young [and perhaps even with adults as well]. In theological terms, the original meaning of mystery was "religious truth via divine revelation," "hidden spiritual significance," or "mystical truth," while in lay terms it meant "secret" or "hidden meaning" (Harper 2001-2013). Children seem to have a natural sense of awe and wonder about the mysteries of the world around them. Perhaps this stems from their meeting with many things that are new to them and not yet understood, and perhaps even unexplainable (Hay & Nye, 2006).

Instead of imposing adult language to explain the mysteries of the world, or even giving faith-based answers, Hay and Nye (2006) suggest attending to the child's imagination, allowing them to give voice to the possibilities. Instead of stifling children's thoughts and beliefs, this might be an occasion to explore big questions with them, such as "Who am I?" "Why am I here?" and "What is my place in the world?" (Hyde, 2004; Gersch et al., 2008). These explorations provide a window on children's understandings of the spiritual and may also help them to gain coherence through narrative (Eaude, 2009; Hyde, 2008). Given that language is often inadequate to capture the fullness and richness of spiritual experience as it is lived, perhaps adults need to observe and listen more attentively to the nuances in children's expressions. Gersch et al. used the term "spiritual listening . . . an attempt to ascertain, not simply the child's views, but more specifically their views about the meanings they attach to their lives, their essential drives, motivation and desires" (p. 226). We need to be attentive to the feelings behind the words in the stories that are told. Intonation, flow, and body language show the

character of feeling underlying expression, pointing to experiences that animate or deflate (Nye, 2009). In our attunement to these expressions, we may be able to discern the spiritual or authentic voice that speaks from the heart rather than from the ordinary voice of the mundane and perhaps less meaningful aspects of life (Nye, 2009). It is a responsibility of caring “not just to hear an accounting, composition, narrative, legend, report or aggregate but to slip behind the word and hear the pain, the experience, the profound spiritual recalibration that is required in this kind of experience” (Moules, 2006, p. 232).

Expressions of intense feeling communicate the value of what is being said. What Hay and Nye (2006) describe as “value-sensing” by children may be seen in their concern for the environment or in their faith in the ultimate goodness in others or in the world. It may also show up in their experiences of delight and despair. For children with serious illness, feelings of despair may have spiritual significance because they point to a sense that the world is not always safe and orderly. For those who believe in god, despair may indicate a sense of abandonment and a view of life as uncertain and unpredictable. This may lead to a spiritual suffering or searching that seeks meaning and a sense of order that brings coherence to the sometimes unexplainable aspects of life.

In order to explore children’s experiences of the spiritual, it is necessary to spend time with them, to attend to their imaginations and their wondering about the mysteries of existing in the world while facilitating expression of their experiences and the feelings associated with them. This approach is similar to Webster’s (2004) existential framework that “centres the concern an individual has for his or her relations with other entities that he or she is in-the-world with, in order to establish a personally significant meaning for his or her existence” (p. 18). In seeking to understand preadolescents’ understandings of spirituality and self, Bosacki and Ota (2000) also found that engagement in story-telling was a means of uncovering the often hidden intra- and inter-personal nature of spirituality. They claim that engagement in reflections on these narratives enabled them to understand how preadolescents perceived these relationships and how these relationships either hindered or helped them in the construction of personal meanings and worldviews.



### **Aesthetics as Source of Meaning**

As noted above, spiritual experience does not fit well with conventional ways of thinking about what counts as legitimate knowledge. Aesthetics may provide a broader perspective in relation to how spiritual knowing might occur. While aesthetic knowing applies to the art of communication and the use of verbal utterances, gestures, and nuances, creative art such as visual art and poetry is another means of communicating felt experiences (Merleau-Ponty, 1962/2002). The various uses of art and story as means of reflection and expression of deeper thoughts and feelings include techniques that have been widely used in psychological, educational, and theological contexts involving children. Cavalletti (1992, 2002), in adapting Montessori philosophy for theological teaching and learning with children, found that through their many drawings, children used their imaginations and created images that revealed an insightful knowing of the spiritual that was often surprising to adults. Art is also purported to be integrally linked to spirituality in which our encounters with the mysteries of life are nurtured and expressed through various forms of art that stimulate the senses and appeal to one's intuition and imagination (Lester, 1985; Pike, 2002; Robinson, 1983).

In the context of exploring the spiritual lives of children, Robert Coles (1990) found that drawing enabled children to elaborate on their spiritual knowledge and experiences when words alone were not sufficient. Further evidence of the powerful therapeutic value of art in helping children to express hidden aspects of their life struggles and in helping others to understand and even identify with their situations can be found in the poignant illustrations in *Childhood Revealed: Art Expressing Pain, Discovery and Hope* (Koplewicz & Goodman, 1999). While the pictures and storied explanations in this book were created in relation to children's therapeutic sessions with mental health professionals and are taken out of context, it is clear that through creating art, the children were able to express hidden thoughts and deeper meanings that may not have been easily communicated in dialogue alone. (See Appendix A for an example of expressions of a 16-year-old female with cancer).

Given the utility of art as a means of expression and its potential for communicating meaning to others (Hess, 2003; Merleau-Ponty, 1962/2002; van Manen, 2002), I asked children in my study to either create a visual depiction (drawings,

collages, paintings) or poetic renderings of their experiences. Children's art in this research context was used not only as means of facilitating their spiritual expressions but also as a tool for eliciting deeper meanings through dialogue with the children.

### **Summary**

Research indicates that children *do* have rich and diverse spiritual lives and that they have a deeper capacity to experience the spiritual than commonly thought. In order to better understand the spiritual as lived by ill children, it is important to hear their stories about life in the context of illness and look for the ways they experience the spiritual. By facilitating expression of experiences of the spiritual through story and art, children are given avenues to express the spiritual as lived. In revealing children's lived experiences through art and story I hope to broaden understandings of how children experience and connect with the spiritual while coping with serious illness. The hope is that findings of this inquiry will provide health professionals with an increased understanding of how children experience the spiritual during illness and how to help them draw on the spiritual more fully as a potential source of coping and resilience. Findings may also contribute to knowledge useful for policy development and in the education of health professionals. In proposing interdisciplinary research to explore spirituality as it relates to the childhood illness experience, I have considered the research and literature from various professions. These contributions will lend richness to the process and analysis ensuring that the findings have relevance to those caregivers for whom they might have the most utility.

### **Chapter 3: Methodology**

Hermeneutic phenomenology is the methodology used to guide this study. Hermeneutics is a philosophy and also an approach to understanding through the interpretation of texts, dialogue, and other symbols of meaning (Gadamer, 1975/2004). Phenomenology, according to Martin Heidegger, is ontological method and is also the practice of scientific philosophy (Heidegger, 1975/1982). In other words, it is an approach to understanding meaning in being. Hermeneutic phenomenology therefore is an approach to interpreting meaning in being, or lived experience, that flows from both of these philosophical traditions.

The methodological approaches used within these traditions vary in some ways in their application and terminology. For this study, I adhere to Heideggerian phenomenology and philosophical hermeneutics. Philosophical hermeneutics was developed by Hans-Georg Gadamer in the mid 1900's and was influenced by Heideggerian philosophy.

#### **Philosophical Grounding**

All efforts to seek knowledge originate in human beings for the sake of the existence of human beings (Heidegger, 1954-1976/1977; 1980/1988). From time immemorial, philosophers contemplated human existence and deliberated on its possibilities. Prior to modernism, science was an activity aimed at understanding the mysteries of human life through rational thought and analysis. Through philosophical discourse, thoughts and ideas were shared and debated until common understandings based on experiences of living in the world led to plausible answers to life's questions.

With modernism came the rejection of this philosophical mode of inquiry, a rejection that stemmed from claims about the inability of philosophical inquiry to quantify knowledge through the "objective" observation of concrete and tangible "things." This shift in thinking led to a more narrowly defined view of science in which knowledge was accepted as valid only through using empirical methods (Slife & Williams, 1995). Empirical method is the legacy of French philosopher René Descartes who believed that the mind (or soul) is separate from the body (Descartes, 1637/1969). Within this dualistic view, research findings were understood to be valid only if they

were objective. Understandings rooted in lived experiences of the world were not accepted as legitimate “knowledge.”

Descartes believed that knowledge gained through sense experience was faulty and sought to eliminate the bias of the “subjective” in scientific investigation. His view was that the only way to certain knowledge was to reduce what is objectively observed to numerical values and concepts that could then be generalized to other contexts (Descartes, 1637/1969). Although this method was designed primarily for the natural sciences such as math and physics, it became reified as the scientific method for all disciplines, including medicine and the human sciences. Through this method, Descartes thought it was

Possible . . . to discover a practical . . . knowing . . . of all the other bodies that surround us . . . [so] we might also apply them in the same way to all the uses to which they are adapted, and thus render ourselves the lords and possessors of nature. (p. 89-90)

Heidegger realized that this method was not helpful for understanding in the human sciences. He was also concerned with how knowledge and technology derived from this tradition was advancing and how it might negatively affect the way we live (Heidegger, 1954-1976/1977). Influenced by Franz Brentano’s (1838-1917) doctoral dissertation, *On the Several Senses of Being in Aristotle* and by his foray back through the history of philosophy, Heidegger started a new project. He wanted to understand being itself. In other words, he wanted to know what makes us human and how we are able to know anything at all. During this project, Heidegger’s phenomenology broke from the phenomenology of his mentor Husserl—that of bracketing pre-understandings (elimination of subjective knowledge), pure consciousness (theorizing about experience), and absoluteness or certainty (Heidegger, 1975/1982). Heidegger’s thought led to revisions of Husserl’s phenomenological method that took into account the contextual and dynamic aspects of life and understanding.

Heidegger’s philosophy is about an orientation toward life in which we understand our knowledge and ourselves as finite and incomplete. As human beings we also have concern for life—our own and that of others. These understandings and concerns are the motivating force behind our search for knowledge that makes life

meaningful and intelligible. Topics for philosophy and scientific investigation in the human sciences are often derived from these concerns (Heidegger, 1954-1976/1977). Phenomenology concerns itself with uncovering what is hidden in our everyday experiences of the world that has relevance to our being (Heidegger, 1954-1976/1977). Problems and questions that concern us grow from our situated understandings of being in the world. This situated knowledge is forever with us, coloring how we see the world and how we take up information in our search for deeper understanding.

As a researcher engaged in hermeneutic phenomenology, the quest for understanding a particular issue comes from one's life, and the process of searching for greater understanding requires a vacillating reflection between one's internal commitment or passion for knowledge and activities that facilitate the search (Bergum, 1991). Danaher and Briod (2005) emphasized that as an adult researching childhood experiences one must employ methods that open the self to the experiences of the child as well as to one's own experiences of childhood in order to better relate to a child's understanding of the world. Given that the researcher represents a filter through which understanding of phenomena emerges, it is also necessary to reveal one's own way of seeing, knowing, and relating (Graue & Walsh, 1998).

Heidegger claimed the starting point for investigating topics of concern in the human sciences is our own pre-reflective understandings of already living in the world. These understandings are based on the fact that we live in a world in which language, culture, and tradition already informs our knowing *before* we separate the world into the objective and the subjective. It is the understanding of a topic before objectification, *as it is lived*, that is the focus of a hermeneutic phenomenological study. Lived experience is not always conscious but is tacit (or pre-theoretical). It is the way we understand the world and engage it in our everyday lives and practices. This is what Heidegger called *facticity*. Facticity presupposes foreknowledge, or what Gadamer referred to as prejudice (Gadamer, 1975/2004). Both Heidegger and Gadamer emphasized that this prejudice or foreknowledge (as much as we are aware of it) should not be bracketed when investigating lived experience, nor can it be, and that it is the ground for understanding the experiences of others and the world. Instead of being bracketed, or set aside in some way, pre-understandings are made explicit as the researcher becomes aware of them

throughout the course of a study to show how they are woven into the process of interpretation (Gadamer, 1975/2004).

The understandings a researcher holds ought not to be fixed and unyielding. Instead, they are acknowledged and put at risk when meeting up with something new or strange in the process of interpretation. This strangeness calls the researcher's previous understandings of the topic into question and compels her to work through this difficulty. The researcher is also shaped by these experiences and understandings as interpretation deepens. This is the transcendent or transformative aspect of the growing understanding of the topic, oneself, and the world as we encounter the strange and attempt to work it out methodologically (in research) and perhaps philosophically (in life). This is what Heidegger referred to as *Bildung*, loosely meaning the development or cultivation of the self, noting that this is always in relation to others and the world (Heidegger, 1954-1976/1977).

Heidegger emphasized that time rather than consciousness is the touchstone for understanding in life. Due to the malleable and developmental nature of such knowledge, Heidegger rejected epistemological method that aims to commit itself to understandings of experience that are rooted in a single moment in time (Biemel & Saner, 2003). In this sense, Heidegger understood knowledge as never certain or static. Instead, it is always open to ambiguity and further contemplation (Greene & Hill, 2005; Nakkula & Ravitch, 1998). In this way, new understandings are always on the horizon and along with them the potential for greater wisdom.

### **Phenomenology**

The study of spirituality requires a special method. I will reiterate a quote from Hardy (1979) as a reminder that when studying spirituality, “the specimens we are hunting are shy and delicate ones which we want to secure in as natural a condition as possible; we must at all costs avoid damaging or distorting them by trying to trap them within an artificial framework” (p. 21).

For Heidegger “science is never a technique. As soon as it becomes one it has fallen away from its own proper nature” (1975/1982, p. 21). What this means is that the way we understand is rooted in life as it is lived, before it is broken down and examined artificially as distinct subject/object relations. As soon as we turn away from this

primordial way of knowing, we have lost important knowledge of life that provides the ground for understanding in the human sciences. Understanding in the human sciences requires an approach that recognizes the value of the researcher's situated knowledge—such as awareness of the topic and tradition, childhood experiences of family illness, and years of caring for ill children—and relies on this familiarity as the ground for interpreting meaning in the lived experiences of another.

Hermeneutic phenomenology is a method that expands and develops in the act of applying it to the topic of investigation. During the interpretive process, as the topic unfolds and reveals what was hidden it also provides clues to how one might proceed with questioning in order to understand it better. Therefore, the conduct of a hermeneutic phenomenological study is not fixed. It moves and morphs with the flux of understanding (Heidegger, 1975/1982). However, that does not mean there is nothing at all to say about how the researcher might proceed.

### **Phenomenological Reduction**

In order to investigate lived experience of the spiritual the researcher must focus on the topic as it is manifested in the lives of the study participants. This requires engagement with participants in a way that provides space for a revealing of the phenomenon as lived. This requires an openness of vision and a sense of curiosity that knows the limits of understanding. For Heidegger, disclosure of meaning in being, which is thought to be related to the spiritual, is found in the way that the mundane, taken for granted way of life is disrupted, calling one out of everyday existence to a state of awareness of one's own finitude and possibilities (Heidegger, 1954-1976/1977; McGuirk, 2009).

The process of understanding is not contemplative at this point but instead can be thought of as an address. How the topic is revealed calls forth the researcher's own pre-reflective understandings of being the world. The term reduction used in this way does not mean that what is revealed is broken down and separated from the whole, and neither is it conscious reflection. Rather, it is a reflexive stance, that encourages the researcher to focus on the topic as it appears in the lived experience of the other and what this evokes based on the researcher's own understandings of being in the world. In this way, the

reduction cannot be understood in isolation. It is bound up with, and moves back and forth along with phenomenological construction and destruction.

### **Phenomenological Construction**

Phenomenological construction requires engagement in dialogue in a way that the topic is revealed and made intelligible in a way that can be coherently organized. This is accomplished through interpretation, which is inevitably tied to the researcher's own inherent knowledge of being in the world (van Manen, 1990). While exploring childhood spirituality in the context of illness, this entailed questioning what it is like to be a child with a serious illness, considering this data along with other data, such as how the topic of spirituality shows up in their lives and in the world. These data are also considered alongside understandings of the topic as presented in the philosophical and academic literature, as revealed in the researcher's own foreknowledge, and in how history has shaped understandings of the topic over time. Interpretations also take into consideration how the topic is implicated in the experiences of participants as it is revealed in their reports and their art in relation to history and tradition and through the researcher's own pre-understandings of what this might mean. This process is repeated as new understandings emerge with each rereading of the text.

### **Phenomenological Destruction**

Within the process of phenomenological reduction and construction, there is a simultaneous effort to set aside prior theoretical notions of the topic and of the participants who are the focus of inquiry to allow lived experiences to be expressed and interpreted unfettered by constraining categories. This is what is termed phenomenological destruction and "only by means of [this] destruction can ontology fully assure itself in a phenomenological way of the genuine character of its concepts" (Heidegger, 1975/1982, p. 23). In this vein, a researcher approaches the research process with openness and humility and without theorizing; expecting to have her own projected pre-understandings challenged by what is disclosed in the encounter with the other.

The phenomenological approach assumes interpretation in which understanding, experience, and expression are intimately connected (Giorgi, 2007). The process is one of understanding that has relevance to the way we live and practice. "In other words, Heidegger was seeking, and believed he found, an a-theoretical, non-objectifying, and



more primordial mode of self-apprehension than self-reflection. This method is the hermeneutical phenomenological approach that Heidegger initiated” (p.72).

### **Hermeneutics**

Heidegger (1949) claimed, “Language is the house of being” (p. 239). It is the way of thinking and of expressing in which meaning in experience is made intelligible. Understanding is a mode of being human and as such is necessarily hermeneutic (Heidegger, 1954-1976/1977). Following Heidegger, Gadamer (1975/2004) extended hermeneutics as a philosophy and an approach to understanding that recognizes the influence of situated knowledge. Hermeneutics uncovers meaning in a fusing of lived understandings through dialectics, unveiling the tacit through language, art, and symbol. Like Heidegger, Gadamer rejected the Cartesian idea of method. Hermeneutics in this sense is an approach to understanding through interpretation that also implies its practical application in life (Gadamer, 1975/2004; Grondin, 1999/2003).

What Gadamer proposed in his philosophical hermeneutics is how language allows dialogue and understanding to take place. It is the mode by which history and tradition form horizons of understanding and situates the researcher hermeneutically already prepared with knowledge of the world, creating the ground for investigating another’s lived experience (Gadamer, 1975/2004; Grondin, 1999/2003). Hermeneutics relies on dialogue, recognizing language as constituting the experienced world. Hermeneutics also recognizes the finitude of language in that language is often inadequate for expressing what one understands pre-reflectively. Language can also be confining when used in the assertion of proof and certainty. The task of the hermeneutic researcher therefore is to interpret lived experience in a way that reveals meaning that is understood pre-reflectively—as lived. This occurs in conversations with study participants when investigating a topic and in conversations the researcher engages in with self and the world while seeking deeper understanding.

### **The Hermeneutic Circle**

The hermeneutic circle is a metaphor for the way the researcher moves within the process of understanding. The assimilation and synthesis that occurs within this process is not meant to produce knowledge that is ideal and definitive, nor is it a circular argument without grounds. For Heidegger, the important step in this process is to enter

the circle in the proper way. The entry point is that place where the topic of our interest comes to meet us as an existential concern or question. It then involves our naïve and a-theoretical projection of pre-understandings onto the possibilities opened by the entry into the circle (Heidegger, 1954-1976/1977). These pre-understandings or prejudices formed by history and tradition are what inform our worldview or horizon of vision. This provides the backdrop for the construction of shared meaning that results in a fusion of horizons and an extension of vision in the working out of the possibilities evoked by the text (Gadamer, 1975/2004). The notion of “text” also applies to practical situations, such as those that arise in healthcare. Understanding the experiences of another requires dialogue and interpretation as a means of arriving at shared understandings of the situation or topic. “Here again, the idea of practice is important, both as a description of what to do and, more importantly, as an attitude of continual opening into possibility” (McCaffery, Raffin-Bouchal, & Moules, 2012, p. 218).

The hermeneutic circle implies a process of vacillating reflection between the parts and the whole of the text (Gadamer, 1975/2004; Grondin, 1999/2003). The process is iterative and seeks deeper understanding through the assimilation of meaning or sense making of the parts in relation to the whole. Each rereading of the text is an opening to see something new. It is a means of enriching or dispelling lines of thinking leading to a deeper understanding of the subject matter. According to Moules (2002), hermeneutic phenomenology

. . . involves careful and detailed reading and rereading of all the text, allowing for the bringing forth of general impressions, something that catches the regard of the reader and lingers, perturbing and distinctive resonances, familiarities, differences, newness, and echoes. Each rereading of the text is an attempt to listen for echoes of something that might expand possibilities of understanding. (p. 29)

Throughout this process, similarities and distinctions are highlighted and brought to bear on individual and collective meanings (Benner, 1994; Benner, Tanner, & Chesla, 2009).

As a participant in the interpretative process, the researcher also has to reflect on his or her own way of seeing the world (Nakkula & Ravitch, 1998). With these

understandings in view, the researcher grapples with the strangeness and familiarity of the text, superimposing upon it one's understandings of the history and tradition that shaped these understandings. In the hermeneutic circle, there is also a growing understanding of self in relation to the topic. As previously held understandings are thrown into relief by the strangeness of the text, the researcher is forced to re-evaluate these understandings. This relates back to page 39, to the German term *Bildung*—loosely meaning the cultivation of self (Heidegger, 1954-1976/1977), and the related notion of tact (Gadamer, 1975/2004). Tact refers to an aesthetic sense or sensitivity in situations in which general principles do not apply. It is an implicit understanding that grows from experience and self-understanding that provides the ground for knowing how to act in certain situations. It is a sense of being able to cope with a situation and know one's way around it (Gadamer, 1975/2004) that relates back to how we practice.

### **Rigor and Authenticity**

Qualitative research is evaluated by different criteria than quantitative studies. In hermeneutic phenomenology, reliability and validity are discussed as issues of rigor (Laverty, 2003), or the procedures followed that make a study believable and trustworthy (Koch, 1996). Authenticity “is based on facts [or data]” and denotes reliability and accuracy. To be authentic, research must be “done in the traditional or original way” (Oxford University Press, 2013)—a way that adheres to the philosophical and methodological tenets that ground it. In existential philosophy, to be authentic is an expression of an “emotionally appropriate, significant, purposive, and responsible mode of human life” (Oxford University Press, 2013). In other words, authentic research in this tradition reveals something that resonates with truth-value that is recognized in experience.

In addition to being authentic, a hermeneutic study must also be applicable in practice. Hermeneutic findings are not meant to be generalizable however. Instead, they are judged for transferability according to their congruence within other contexts. Rich descriptions of the phenomenon, the participants, and the contexts from which they are drawn provide the background for determining fit in other settings, allowing the receiver of findings to judge the correspondence between contexts.

The following paragraphs outline the procedures followed, or the rigor employed in my efforts to ensure authenticity of study findings. I will also elaborate on what it means for findings to be transferrable and what I did to provide the context for informed judgement of the congruence of findings in other settings. In this elaboration, I will also discuss how findings of hermeneutic studies can be transformative by providing understandings that open possibilities for new ways of thinking and practicing.

### **Ways of Ensuring Authenticity**

Reflexivity is one way to ensure authenticity. Reflexivity in the hermeneutic research process entails a focusing of attention on the topic, attuning oneself to personal and traditional assumptions and their implications for challenging, deepening, and refining understandings in the hermeneutic circle (McCaffrey et al., 2012). Although reflexivity is one way to ensure authenticity of the research findings, I also used other strategies. One strategy was to gather information from various sources (Maxwell, 1996; Quinn Patton, 2002). The most important source of data was the children themselves. I also gathered artifacts to ensure the authenticity of findings (Graue & Walsh, 1998) in the form of artwork by the children and observed for behaviours and emotions within the dialogic relationship with the child (Maxwell, 1996).

Another way I ensured the authenticity of the findings was to get feedback from colleagues to ensure that the interpretations and meanings constructed were born from the actual expressions of the children (Guba & Lincoln, 1989; Lincoln & Guba, 1985; Maxwell, 1996). I also attempted to collect rich data from diverse perspectives, which began with purposive sampling (Guba & Lincoln, 1989; Maxwell, 1996; Quinn Patton, 2002) of children with life-limiting or life-threatening illness. Reflective memos of my own reactions during the research process, and how my interactions influenced the process, were also a means by which I ensured authenticity (Maxwell, 1996). “A credible voice conveys authenticity and trustworthiness . . . The researcher’s focus becomes balance—understanding and depicting the world authentically in all its complexity while being self-analytical, politically aware, and reflexive in consciousness” (Quinn Patton, 2002, p. 41).

## **Transformation, and Transferability**

In presenting the findings of this research, the purpose is not to generalize or to propose a theoretical stance but to provide a rich description of the phenomena through evocative writing (Gadow, 2000; van Manen, 1990, 2002) that speaks to others and prompts them to re-think their present understandings of the realities of contemporary children's lives (Nakkula & Ravitch, 1998). "Artistically oriented qualitative analysts seek to engage those receiving the work, to connect with them, move them, provoke and stimulate" (Quinn Patton, 2002, p. 548). Art in its many forms—visual, musical, literary, and poetic—has the ability to express felt experience to an "other" through direct contact. It is within this relational space between a person and phenomena in the world in which time and space are transcended, meaning is captured, and the person is changed as a result (Merleau-Ponty, 1962/2002).

In order for the findings in this study to be transformative, it is necessary to construct a rendering of the phenomenon that speaks to others in a way that they are taken in by it and are able to see themselves in the rendering (van Manen, 1990, 2002). In order to speak to others through a co-constructed rendering of children's experiences of spirituality I used art in the form of children's drawings and attempted to present the findings in a way that would resonate and perhaps prompt the reader to reflect on their own experiences (van Manen, 1990, 2002). I also used artifacts (Graue & Walsh, 1998) in the form of conversations held with parents and symbols of meaning as they had relevance in the children's lives (van Manen, 1990).

Evocative writing enables the text to call another forth to identify with the meaning embedded in the rendering. This "evoking experience through pathic means is the manner in which human science presents the data of inquiry" (van Manen, 2011a). It is when the reader or audience contemplates the rendering and then reflects on his or her own experiences, once again to reflect back on the source of the rendering to find shared meaning. "The intent of writing is to produce textual portrayals that resonate with the kinds of meanings that we seem to recognize in prereflective experience" (van Manen, 2011b).

Within the play of words, there is an attempt to reach the reader through pathic means by bringing them into direct contact with a primordial sense of meaning derived

from their own experiences of being in the world (Gadamer, 1975/2004; Grondin, 1999/2003). Hermeneutics uses language in a way that evokes something deeper—something that lays hidden but is nevertheless a truth of our being. It is how the particular is able to say something to us in a personal way and in a communal way, perhaps even in an ethical, moral, or political way.

In order for the findings of a hermeneutic study to be transferrable, they must speak to readers and grab their attention, attuning them to the topic, the context, and to their own practices. The next step is to determine congruence of fit. To assist the reader in determining the fit of the findings in other settings I provided detailed descriptions of the context (Maxwell, 1996), the participants, and the phenomenon. This ensured that the receivers of the research could make an informed decision about its usefulness in their own practices.

### **Summary**

As a hermeneutic phenomenological researcher interested in exploring childhood spirituality, I must attend to my personal, philosophical, and methodological assumptions. These assumptions not only guide the research process but also serve as signposts that remind me to be explicit about how these assumptions are woven into the findings. In the next chapter, I will discuss the participants and specific procedures followed for recruitment and for ensuring ethical conduct. I will also elaborate on the process of data collection and analysis, showing how I adhered to the philosophical and methodological underpinnings of the study.

## **Chapter 4: Study Procedures**

### **Participants**

Purposive sampling was used to recruit children nine to fourteen years of age who were living with cancer and cystic fibrosis and who were willing and able to talk about spirituality. Choosing children nine years of age or older increased the likelihood that participants would be able to understand questions and have the language to express themselves in relation to the topic. Having a narrow age range also ensured some homogeneity of the sample with regard to language ability. Hermeneutic phenomenology is similar to other interpretive phenomenological methods in which “sampling tends to be purposive and broadly homogenous” (Brocki & Wearden, 2006, p. 95). These methods aim for “a more closely defined group for whom the research question will be significant” (Smith & Osborn, 2008, p. 56). I chose children with CF and cancer because both are life-limiting and life-threatening illnesses. Although CF and cancer manifest in different ways, they share existential elements that relate to the spiritual.

If a child had cancer, they needed to be within one year of completing treatment or on active treatment at the time of the study. Another important inclusion criterion was fluency with English, due to the importance of language in understanding. Children being treated for brain tumors were excluded due to the potential for cognitive impairment that might have made it difficult for them to respond to some of the interview questions. Children who had recently relapsed, were dying, or were within one month of diagnosis were also excluded, as it was felt that children and families would likely be under tremendous stress at these times. Choosing children with cancer who were still receiving treatment or were within one year of finishing treatment ensured that children had a fresh perspective on their illness experiences and could speak to the impact this may have had on their contemplation of the spiritual.

The final sample was comprised of eight children ranging in age from nine to fourteen years (six males and two females) who were being treated for cystic fibrosis (four) or cancer (three) or who were within one year of being treated for cancer (one). Hermeneutic phenomenological studies do not require a large number of participants. In fact, smaller numbers are preferable because they allow for deeper analysis of the text. Deeper analysis is also the aim of interpretive phenomenology, a tradition that is

“intellectually connected to hermeneutics” (Smith & Osborn, 2008, p. 53). In a literature review of 52 interpretive phenomenological studies, Brocki and Wearden (2006) found that the researchers interviewed anywhere from one to 35 participants. Sixteen of these studies had eight participants or less. Brocki and Wearden claimed there is an emerging preference in interpretive phenomenology for smaller numbers of study participants in order to avoid missing the subtle nuances and meanings conveyed in particular passages. “A small sample size of up to about ten participants” is more amenable to the iterative and cyclical nature of analysis (Smith, Jarman, & Osborn, 1999, p. 225) and allows for context and depth of iteration within broader frameworks of meaning.

## **Procedure**

### **Recruitment Process**

Once the IWK Health Centre (IWK) Research Ethics Board approved the study, letters of invitation were sent to families of eligible children. IWK physicians who were familiar with these families identified eligible children and letters were sent from the clinics where they received care. The invitations to participants included an introduction letter to families along with an explanation of the study (See Appendix B, C, and D). A phone number and an email address were provided so that children and parents could make further inquiries about the study prior to making a decision to participate. They were also encouraged to use this contact information to indicate that they did not wish to participate or that they did not wish to be contacted. In the letter, it was indicated that if I did not hear from families within two weeks, I would contact them by phone to inquire about their interest in participating.

The process of recruitment happened in two stages. The first round of recruitment began with letters of invitation sent on May 28, 2009 from the oncology clinic to 13 families of children with cancer. On August 13, 2009, letters were sent to 17 families of children with CF. Follow-up phone calls I made to families resulted in only four participants agreeing to take part (two from each illness group). Months later, with children becoming eligible due to age or trajectory of illness (children with cancer), the availability of potential participants offered new opportunities for recruitment. After receiving ethical approval to re-initiate the recruitment process, eligible participants were again identified by their respective physicians. Letters were then sent from each clinic



(late May 2010) to families of eligible children (fourteen with cancer and twenty with CF), some of whom were on the initial recruitment list.

Of those contacted, four additional participants agreed to take part for a total of eight. All follow-up phone calls I made to families were documented, and if any information relating to their decision about non-participation was obtained, I recorded this as well. For the most part, families did not give reasons for declining to participate. A few families indicated that there was a lot going on in their lives as a reason for non-participation. It is difficult to speculate why families decided not to participate. Perhaps the sensitive and often private nature of the topic was an influencing factor. It is also possible that some families will have conflated the spiritual with the religious despite providing clarification in the Parent Authorization Form (See Appendix C). This may have led to the reluctance of some families to participate if they did not consider themselves religious.

When parents indicated their children's interest in participating in the study, I clarified information and encouraged questions. If there was agreement to participate, I arranged a meeting to review the consent forms and proceeded with the first interview pending the child's willingness to take part in the study. The families had the choice of meeting at the hospital or in their homes. Arrangements for the place and time of the meetings were negotiated in consultation with a parent as transportation and or invitation to the family's home was contingent on convenience, parental availability, and preference.

### **Consent and Assent**

With emphasis on soliciting children's views and their free and informed willingness to participate, I sought verbal assent from the children (See Appendix D) and a signed consent from parents (See Appendix C). Although a collaborative process of decision-making between parents and children was encouraged, addressing assent information specifically to the children let them know that their views were important and that the final decision to participate remained with them. In order to ensure that both parents and young participants understood the purpose, expectations, potential harms, and benefits, language explaining these in the forms were tailored to a grade eight reading level for parents and a grade four reading level for children. The consent and

assent forms also stipulated that participation was voluntary and that non-participation would not affect the provision of treatment or services offered by the IWK now or in the future. The decision to discontinue participation in the study was made by one child (Jake) and his family due to deterioration in health. A desire to opt out of an interview occurred only once before beginning the third interview with one of the children (Matt). At the conclusion of each interview, I also asked each of the children if they were interested in meeting again. All of the children indicated their willingness to do so. See the section on data collection methods below for more information about the interview process.

### **Ethical Considerations**

Helseth and Slettebo (2004) explored children's understandings of the research process in the context of conducting qualitative research with children whose parents had cancer. They contended that it is not a question of whether children should be involved in research but how to design research in ways that minimize risk of harm. The Tri-Council Policy Statement (CIHR, NSERCC, & SSHRCC, 2010) asserts that potential harms induced by research with children, and especially ill children, require special consideration. Not only should these potential harms be explicitly explained to participants and their guardians, but also careful consideration of how to minimize these harms is an imperative.

Given that as the researcher I was part of the dialogic and interpretive process, it was also important to be cognizant of the influence I had on the setting and the individuals in the study. As an adult, I had inherent power in relation to child participants (Graue & Walsh, 1998; Greene & Hill, 2005). One way to combat this phenomenon is for the researcher to position herself in the role of the learner, interested in understanding what it is like to be a child in the particular context of interest (Graue & Walsh, 1998). This stance also gave children the sense that their knowledge was valuable and that their views were integral to helping others understand their experiences.

### **Minimizing Harm**

One potential risk of questioning children about illness and their spiritual experiences and understandings is that existential issues and fears about death might come to the fore. Although thoughts and fears about death were found to be already

present in the lives of the children in this study, verbalizing them can sometimes lead to emotional upset or spiritual distress. To minimize the impact of this potential risk, I encouraged children to voice their various feelings and thoughts according to their comfort level and provided support appropriately. I also observed carefully for verbal and non-verbal signs of distress or disinclination to discuss certain issues. I ensured my commitment to participants' well-being by being attuned to their emotions. I remained engaged during the interview, allowing them the opportunity to express their emotions freely. I also gave participants the opportunity to discuss their distressing thoughts and feelings or to stop the interview if they wished.

I also inquired about the child's personal support networks by asking them whom they would talk to when they have a serious problem or concern and encouraged them to seek support from them if necessary. Contact information for psychosocial and spiritual supports at the IWK was also provided to families in the event that professional counseling was needed. Letters of support from IWK spiritual and psychological healthcare providers can be found in Appendix E.

Another consideration in minimizing harm was to be cognizant of the medical condition of the ill child. As noted above, if the child was feeling unwell or was in hospital receiving treatment, I inquired about the child's desire to participate. I then suggested meeting at another more convenient time when the child was feeling physically well or gave the option of discontinuing participation. This eliminated any pressure on the children to participate and enabled parents to concentrate on family needs. Furthermore, in order to discuss issues of spiritual meaning, children should be free from any distress that might hamper their ability to concentrate on or discuss issues beyond their own immediate physical needs.

### **Potential Benefits**

Expressions of fear, negative feelings, and or spiritual distress had the potential to benefit children because it may have led them to a greater understanding of their own feelings and spiritual experiences. It may have also encouraged dialogue among family members in a way that was spiritually supportive. Giving children a non-judgmental and private forum for discussing sensitive issues may be the first step in them opening dialogue with others who could provide needed support and nurturance. Talking about

spiritual issues had the potential to increase children's awareness of how the spiritual might have an influence on their experiences of illness. One other potential benefit of this study is that children may have also experienced a sense of agency in being able to contribute to knowledge that has the potential to help others.

### **Confidentiality**

Confidentiality of participants was safeguarded by using pseudonyms and direct quotes in ways that did not reveal the identities of speakers. To accomplish this, contextual information in the storied renderings was sometimes hidden (such as the type of cancer) or omitted, such as familial structure, identifying demographics, or situations that could be deciphered by caregivers who know the families well. These omissions of detail were balanced with the need to provide some context to create depth and ensure authenticity of the data.

In relation to confidentiality of information shared within the family, each child was given the choice to have a parent present during their interviews or to meet with me alone. None of the children protested their parents' choices not to be present, nor did they indicate a strong preference for them to stay for the interviews. All but two children had their parents present for at least the first interview or a portion of it, and I was able to meet with all children alone at least once. Without expressed verbal assent by the children, things said during the private interviews were not shared with their parents. Children were aware that I would have to tell someone if they told me they were in danger of harming others or of being harmed.

Children were made aware that their words would be shared in a way that did not identify them. Parents were also made aware that the de-identified, coded audio and text files of their children's interviews would be kept safe on an encrypted, password protected portable hard drive that would be kept in a locked drawer in my home office. Only I have access to these files and they will be destroyed five years following the publication of the study. Consent forms with a key that links the code names to the actual participant names have also been kept in a locked file cabinet in my home office.

### **Data Collection: Interviews**

The interview questions were developed based on the description of spirituality that guides this study. I describe spirituality as relating to our connectedness with self,

other, world, and the transcendent, which informs how we find meaning and purpose in life within and outside of religious understandings. Questions were open-ended and arranged by topic, i.e. relationships with self, other, world, and the transcendent. I also asked children what it is like to be ill and explored the impact this had on their lives and various relationships. Each interview was conducted using an informal, semi-structured conversational style that was guided by key questions designed to elicit children's reflection about their spiritual knowledge and experiences, relationships, and meanings in illness (See Appendix F). By employing a flexible approach to interviewing, the direction of the conversations was co-created as relevant lines of inquiry arose from the discussion. The topics children focused on during the interviews said something about what was of value or concern to them—what they cared about or what had meaning to them. I used these shifts in conversation to explore issues more deeply when they had relevance to the topic.

I met with each of the children two to three times, each for one-half to one full hour on average, with the exception of the one child whose health condition precluded his ability to continue participating after the first interview. Of the remaining children, I had three interviews with five of the children and two interviews with two others. In the latter two cases, one decided not to continue in the study. In the other, I had exhausted approaches used with other children, and despite revisions to questions, the participant had nothing new to share.

I began the interviews with an introductory session in which I spent time explaining the study, answering questions, and obtaining signed parental authorization and child assent. After assent and authorization were given, the remainder of the first interview consisted of getting to know each child by inquiring about their interests, activities, and important relationships in their lives followed by questioning about their experiences with illness and their understandings of the term spirituality. During this interview, children were also given the opportunity to draw a picture or write poetry that depicted their experience with illness or their spiritual understandings and experiences. Those who did not wish to write poetry or draw were not expected to do so. None of the children opted to write poetry, but six out of eight children decided to draw some pictures. These drawings were used to elicit deeper expression from the children. I also

asked children to talk about the meaning of their artwork. Digital copies of children's drawings were made so that the originals remained with the child.

Prior to the second interview with children, I would listen to the previously recorded interviews to gather thoughts, reflect on what was said, and plan the approach for the next interview (Crist & Tanner, 2003). Questions were then developed based on this review. Similar to the original interview guide, these questions and probes provided a general guide and a means of orienting the interview toward the topic of interest and to the child's previous expressions in an attempt to elaborate on understandings that were puzzling or were not fully articulated in prior interviews (Benner et al., 2009). I also reflected on my interview style, which led to a conscious effort to avoid closed-ended questions or ones that were too leading while looking for alternate ways of eliciting dialogue from children who were less verbose. This process of reflexivity with regard to the direction and type of questioning along with careful attention to children's responses in situ led to a change in approach that is consistent with the emergent nature of hermeneutic phenomenology.

In the subsequent interviews, alternative ways of eliciting dialogue came in the form of written questions that were given to the children following the first or second interview. These questions were based on queries that arose during the previous interview and with those of other participants and allowed children time to reflect on the questions and the meanings they held. The children were also invited to draw pictures or write poetry that would elicit deeper thought and other forms of expression.

The second interview usually began with a review of what was discussed in the previous interview and an inquiry into any thoughts that may have arisen since our last conversation. The focus of the second interview followed relevant lines of inquiry arising from the first interview and explored children's relationships with self and others in the context of coping with illness. If the children had thoughts or drawings to share, we often began with these as a means of eliciting new meanings that provided segues into new lines of inquiry. At the end of this interview, children were again given the opportunity to draw pictures or write poetry that depicted their spiritual experiences, their relationships and felt connections, and or their experiences of coping with illness.

The third and final interview mirrored the second in that the main issues arising from the previous interview were reviewed along with any drawings or other symbols of meaning. I also asked the children to tell me if they had thought about our last conversation and if they thought of anything new that they wanted to share. After addressing any new thoughts expressed by the children, I proceeded to expand my understanding of issues raised in the previous interview. I also posed questions about connections and relationships with the surrounding world and the transcendent if this was not covered in the second interview. During interviews with the children, I paid particular attention to children's interactions with family members and any others present and was attentive to non-verbal behavior and tone throughout the interview process. Following each of the interviews, I made field notes that were later used to facilitate a deeper understanding of what was expressed (Vandermause & Fleming, 2011) as well as to enrich the context of the findings.

### **Analysis**

The consent process and any conversations with families were documented in the form of memos to provide evidence of ethical conduct and context for later interpretation. Interpretation proceeded as I reviewed audio recordings of previous interviews in preparation for subsequent interviews to look for partial understandings that needed clarification or elaboration. I then structured some additional open-ended questions to help uncover deeper understandings or new lines of inquiry based on this initial interpretation (Benner, 1994). In this initial review of interview data, general thoughts emerged. I documented these thoughts as part of the reflexive process that enabled me to keep track of my evolving interpretations.

Interpretation continued as I transcribed each of the interviews verbatim. I listened for tone, non-linguistic communication such as laughing, sighing, crying, and sarcasm, and relevant background noises and included them in the transcripts. These observations, along with field notes describing interactions and conversations with families added richness and context to the dialogue and were analyzed simultaneously as part of the transcripts (Crist & Tanner, 2003). At times, while reading texts for meaning, I would return to the audio files to listen to certain passages. This helped me to remain

engaged in the lived experiences as they were expressed, and contributed to my depth of understanding of the data.

Once I transcribed all of the interviews, I carefully reviewed each child's interview transcripts, searching for what the text revealed about the topic along with those excerpts that stood out to me as particularly interesting. As I proceeded through each interview, I made annotations of my initial thoughts. I also marked the text for interpretation (Benner, 1994), which enabled me to search the text for exemplars that spoke to new understandings that arose as interpretive understandings shifted in the process of analysis. This allowed for the back and forth movement from understandings of each participant's narrative text to the whole of the context from which they were taken and to examine these understandings side by side with cases and examples from other participants in relation to the narrative as a whole.

As I carefully reviewed each transcript, I reflected on the meanings that arose and began to write. As I analyzed each participant's interviews in depth, I took note of those narratives that expressed meanings that stood out, due to their ability to convey meaning artfully or were unsettling or challenging with regard to my presumptive understandings of the topic (Benner, 1994; Moules, 2002). Narratives that provided vibrant examples of meaning in illness, spiritual experience, spiritual distress or questioning, or felt spiritual connections or disconnections were noted and included in the initial writing (Benner et al., 2009; Benner, 1994). This enabled me to appreciate the diverse nature of spiritual experience among the children and also to challenge my own assumptions and open my eyes to seeing the spiritual in the mundane, everyday experiences in the children's lives (Benner et al., 2009).

It was during the in depth analysis of each child's transcripts and the writing process that I began to see more clearly the connections to meanings arising from interviews with the other children. When new understandings emerged, I would note these with an overall name. I then reread all of the children's interviews looking for other examples of similar meaning. I also looked for quotes that challenged my thinking about the prevalence of shared meaning, or that conveyed different understandings about spirituality. This process of moving between the parts and the whole led to evolving



interpretations at each step. Understandings were documented as they emerged or changed during the interpretive process.

Once I had written an in depth analysis of a child's narratives, I elicited feedback from a committee member with expertise in the methodology and subject area to ensure that my interpretations were arising from the data and to provide alternate interpretations that stimulated new lines of thought (Benner et al., 2009; Crist & Tanner, 2003). While awaiting feedback I continued an in depth analysis of each child's transcripts and once again elicited feedback on subsequent interpretations.

Once I had some initial feedback on the congruency of my interpretations with the text, I returned to the transcripts of all the children and began exploring new lines of thought. During this process, I searched for additional meanings, eliminated interpretive dead ends, and elaborated on those meanings that resonated or challenged, again looking through all transcripts for exemplars and points of departure. During this process, I paid particular attention to how my own assumptions and prejudices were implicated in the interpretation while not losing sight of what each child's particular story was revealing (Crist & Tanner, 2003).

The process of interpretation was iterative and intensive and did not end when I stopped working for the day. Because the topic of spirituality is relevant to being itself, I had the opportunity to speak with others (mostly adults) about the topic and I was acutely alert to seeing examples of spiritual expression in the world around me. I was also able to see connections in the literature that were brought to bear on the interpretation of meanings. Although these changes in thought were not recorded, they did influence my thinking and allowed me to see the commonalities in thoughts and experiences encountered with others in my daily life and in the cross disciplinary literature with those that were expressed by the children.

### **Summary**

In the forgoing chapter, I described the criteria for participation and provided rationale for the choice and number of participants in this study. I also explained the procedures followed during recruitment and while obtaining assent and consent, and showed how I attended to ethical issues. Finally, I explained how I collected and analyzed the data, showing how this was congruent with the methodology that informs

the study. The following five chapters will focus on the findings and the discussion of the findings with relation to what is in the literature. This will begin with children's stories about meaning in illness.

## **Chapter 5: Children’s Stories of Illness, Meaning, and the Spiritual**

The stories I am about to share with you first and foremost belong to the children you are about to meet. In my interpretation of their experiences, I hope to deepen understanding of how the spiritual is lived by them as they manage serious illness. The spiritual is embodied in children’s experiences of illness and in their relationships with self and others. In this reading of the spiritual, “others” include people, objects, the environment, systems, and institutions, as well as the transcendent or a transcendent other. The spiritual as lived cannot be reduced to claims or beliefs but rather shows itself in “the tone, the attitude, leaning, and quality” of a life (Scott & Evans, 2010, p. 156).

I looked for the spiritual in the in-between of the stories that the children told about illness and their relationships, in the way they viewed the world, and in how they met and moved through the challenges of life. Findings are presented in the following chapters, beginning in this chapter with “meanings in illness.” This chapter is followed with findings about children’s relatedness to a transcendent other (Chapter 6), understandings of spiritual connectedness and children’s sense of continuation beyond the physical (Chapter 7), the spiritual in play (Chapter 8) and the spirituality of family and community (Chapter 9). As patterns emerged during the analysis of the text, they were organized into interpretations. Within each interpretation, understandings from one or more of the children were provided as exemplars. While in some instances, there were patterns of shared meaning, in others there were juxtapositions and tensions that reveal possibilities for multiple and sometimes opposing meanings.

Relevant literature, anecdotes, and pertinent links that support and broaden interpretations are intertwined with the findings rather than being provided in a separate discussion chapter. Integrating findings within a broader dialogue prevents a fracturing of the text and is congruent with a hermeneutic approach. Hermeneutics is the theory and practice of interpretation that leads to understanding. Such understanding however is always open to further interpretation or even alternate interpretations depending on where the reader is situated. When done well, hermeneutics invites readers to engage with the text, to discover points of resonance and perhaps contention that leave understandings open, always ready for the arrival of something new (Moules, 2002).

Meanings in illness and in life relate to the spiritual. When illness disrupts life, we tend to look for ways to make sense of it, to put the pieces of our lives back together. We seek coherence and look for ways to integrate illness into our lives in such a way that it makes life livable. The understandings children had of illness are presented below, and the interpretation of these lends context to the sections that follow. Meanings in illness are interpreted here in relation to the spiritual.

### **Illness as a Gift of Challenge**

#### **Amy (13 Years)**

Amy is a thirteen-year-old girl with cystic fibrosis (CF) who lives in a rural community. At the time of the interviews, she had recently completed grade eight at the local junior high school. She lives with her family, surrounded by extended family members, friends, and trusted adults who were considered important and supportive influences in her life. There was open communication between Amy and her mother about her illness and what impact this might have on her present and future health. Amy and her family were also active members of their church and had a strong connection with their church community.

I met with Amy on three separate occasions, twice at her home and once at the hospital. Throughout our conversations, Amy had no difficulty articulating her beliefs and thoughts. Her ability to reflect deeply on experiences was evident and she was very candid in the sharing of her stories. During the first two interviews, Amy's mother was present in the background. Amy was open to having her mother present and sometimes deferred to her for clarification during the interviews.

After Amy explained what god and her faith says about why people get sick (described in a later section), she was asked how this applied to her having CF. Amy went on to describe how she acquired the disease.

Amy: The gene was carried through from my mom to my grandmother. . . . [My nanny] blamed it all on herself for giving mom the gene, but you can't control that. . . . I'm glad she gave me the disease because I look at it like a challenge and I'm ready to face it . . . so I'm going to go through it and I'm going to win the challenge. . . . I helped my nanny through it because I know how bad she felt, and I told her not to. It wasn't her fault at all. I wouldn't blame anyone for my disease. . . . I think people should look at it as a challenge . . . that they have to get through it. [I think people should] not give up or stop doing anything. [They should] do more

things because of it and just continue life and have a better outlook on life.

Within Amy's story, multiple voices coalesce into a coherent whole, resulting in a story that can be shaped and reshaped. In Amy's search for understanding about her illness, a family's genetic legacy is revealed to her. This is a family story that has been long-lived by its members, taking root long before Amy's voice as the central character takes the stage. As Amy enters the story, she molds the story and makes it her own, transforming shared meanings from ones of guilt and remorse to ones of forgiveness and triumph.

Instead of blaming others, Amy viewed her genetic inheritance as being beyond anyone's control and chose to see her illness as a gift of challenge that she will win. The 15<sup>th</sup> century meaning of the word challenge is "a calling to fight" (Harper, 2001-2013). As Amy was called to fight an illness that was passed on to her from her grandmother and mother, she realized the need to do more things to preserve her health and well-being. In order to continue living a healthy life, she had to adhere to a demanding treatment regime and attend to her bodily needs as prescribed by her illness. In essence, this was a fight for her life—a struggle to maintain bodily function against a disease that was unrelenting.

For the child with CF, there are no before and after images. The atmosphere of fight is one that is as intrinsic to his or her life as CF itself and, as they become increasingly aware, a battle in which they are signed up for life, however long that might be. (Jessup & Parkinson, 2010, p. 357)

Despite acquiring an illness that presents many challenges and limits the length and quality of her life, Amy chose to see it as a challenge that she was ready to face. In Amy's view of self and illness, CF was the adversary. She found purpose in her illness as a "call to fight" that was inextricably linked to her mother and grandmother and to her very existence. Finding purpose in adverse life events not only gives meaning to a life of ongoing challenge, it mitigates negative appraisals that threaten to color a life grey with feelings of hopelessness and depression (Raftopoulos & Bates, 2011). Within this *illness as a gift of challenge* narrative Amy was fortified. She was animated by a belief in herself as capable of winning and transcending the effects of her disease. Her tone, attitude, and leanings denote a way of living the challenges of her illness.

Amy's view of life and illness as comprehensible, meaningful, and manageable and of self as transcendent is reminiscent of notions of resilience. By integrating illness meanings, Amy seems to garner a "sense of coherence" (Antonovsky, 1979)—a way of maintaining wholeness and health that may mitigate risk of future illness crises. From this view, what is happening here seems akin to resilience.

Despite Amy's knowledge of some of the life-limiting aspects of her disease, she looked toward the future with hope. Her dreams and aspirations were not unlike those of other girls her age, and as she anticipated the future, she considered how her disease might influence later life decisions.

Amy: There's one part in my disease that's hereditary, so you can have kids [with CF]. I never thought about never having kids. I always thought when I was growing up, I'm going to have kids . . . and then I'd be like, 'Oh yeah, my disease says I can't have kids.' I'm like, 'Whatever, I'm having kids.' I never thought of that part. It was just something that really didn't exist in my head. Even if I can't have kids, I'd like to adopt kids. . . . And if I had kids, I hope that they wouldn't have my disease.

As Amy entered her teen years, she became aware of how her disease might influence her future decision to have children of her own. This was not something that she had really thought about until recently. With growing knowledge and maturity, she was making connections between her illness, heredity, and biological reproduction. Children who live with chronic illness look toward the future with the same hopes and aspirations as their healthy peers. However, growing awareness of the limits that illness places on well-laid intentions for the future, children are forced to re-evaluate life and revise previously held meanings, hopes, and dreams (Taylor, Franck, Dhawan, & Gibson, 2010).

Regardless of the risk of having a child with CF, Amy declared that she would have children anyway. She said this with a nonchalant dismissal of her disease, maintaining that she will do what she wishes in spite of "what her disease says." She planned to beat her disease by following her own mind and by pursuing her dream to have children of her own. Infused with the will to fight, she rose above her disease. She transcended her disease in her view of herself as moving through it and beyond it. She wanted to give life to another—a part of herself, minus the disease. The giving and

nurturing of life in the eve of her own existence extends the meaning of her life into the lives of generations to follow.

While echoes of “what her disease says” lingered in her mind Amy had already anticipated the possibility that this dream may not become a reality. Living with this uncertainty, she had already decided on adoption as an alternative so that her aspirations to become a mother were still attainable. Either way Amy triumphs over her disease, beating it by finding ways to circumvent its threat to her intentions and life goals. Although she was not ready to give up hope of bearing children of her own, she also realized that any children she gives birth to will inherit the CF gene from her. Nevertheless, she maintained hope that they would not get her disease and have to endure the legacy of CF.

Dealing with the daily responsibilities of managing her disease changed the way Amy looked at life and the way she viewed herself in the context of her illness.

Amy: I think it [CF] makes a difference [in how I look at life] because I know how precious life is and how it can all change in a second. It only takes one thing to go wrong. By not doing my mask or not taking my pills, you can get sick and you can wind up in the hospital just like that . . . I think if I weren't to have the disease then I would be different. I'm never going to get rid of the disease . . . but, if for some reason they were to have a cure to get rid of it, I would definitely take it. I'd do a lot of thinking before, even though I know in the end I'd take the cure . . . And I'm really a different person the way I've matured too, because I have to be more mature with the disease. I have to remember to take my mask and take my pills and so I have a little maturity there. I kind of depend on myself, but if I [didn't have CF] I wouldn't be as mature.

Amy lived her life with the awareness of how quickly her life could change. Unlike healthy children her age, she was reminded daily that she lived with the unpredictability of a life-threatening and life-limiting illness that dogged her at every turn.

Unpredictability kept her grounded in living by reminding her of the extra effort she must make to stay healthy. It reminded her of the preciousness of life, its value, and the cost of not attending to bodily needs as prescribed by her illness. An illness that threatens one's existence, or even one's way of life, calls for understandings that arise from the depths. It requires a drilling down and a contemplation of those things that hold meaning in life. In doing so, Amy found a way to live a life of illness and uncertainty, viewing illness as a challenge and an opportunity for growth.

The constant daily reminders of illness, along with episodic illness crises, “situate those with CF in a life-and-death binary that is the essence of living that life” (Jessup & Parkinson, 2010, p. 361). Despite children’s developing understandings of their chronic illnesses as life-threatening, strength can be found in a philosophical stance that is intertwined with meaning making (Jessup & Parkinson, 2010). As Amy lived the uncertainty of her illness, she gained new understandings of self, illness, and future as she grew. Existential threat seemed to conjure meanings that fuelled a spiritual or philosophical worldview enabling her to maintain strength and hope in the midst of crisis and ongoing uncertainty. In finding meaning and purpose in her illness as a calling to fight, she seemed to draw on energy that enabled her to view her illness as manageable and self as transcendent. As she connected with her inner self and integrated illness as a part of who she was she was transformed and perhaps more resilient, better prepared for the ongoing struggle that is inherent in a life besieged by CF.

Amy’s view of illness as a challenge and a teacher echoes the findings of Canda (2001), a social worker who not only interviewed many adults with CF but also lived with CF as well. Canda believed that pain and suffering, if handled correctly, could teach us to live more fully and with more quality. With knowledge that CF results in a shortened life, one has a heightened sense of the preciousness of life, leading to a searching of those elements that add quality to living, something that was also revealed in Amy’s experience. In an interview with Canda’s brother Tom, who also had CF, Tom explains that he would be at a loss if he were born without CF and that he has viewed his illness as the impetus for tremendous personal growth and identity formation.

But making the choice to use illness for personal transformation requires courage, perseverance, and spiritual sophistication. It is all too easy for people to feel worn down by illness and thoughts of mortality. But when we make the choice for wellness, we can find many spiritually-based helping and healing activities and support systems that promote physical health and overall well-being. (p. 112)

Like Tom, Amy maintained a positive outlook on life despite the many challenges of her illness. Experiences such as these speak of the enduring quality of self-transformation that can take place in the face of adverse life events. “Peak experiences”



in childhood that result in directedness in life, a formation of values, a sense of self, orientation, relational capacity, and attitude, are indelibly tied to one's spiritual development (Scott & Evans, 2010). Despite the unwanted presence of illness, Amy seemed to glean from it a purposeful way of looking at life that accentuated the positive rather than the negative in living CF as a gift of challenge.

### **Illness as Unspeakable**

#### **Lucy (13 Years)**

Lucy is a thirteen-year-old girl who also has cystic fibrosis. Like Amy, she lives in a rural community and at the time of the interview had also just completed grade eight at the local junior high school. She lives with her family and a number of family pets. She also talked about having many friends and about her enjoyment of swimming, hockey, soccer, and lacrosse. I met with Lucy at her home on two separate occasions, and it was decided by Lucy's mother that we should talk alone because she believed that Lucy might be more open if her parents were not present. Prior to meeting Lucy, her mother and I had an opportunity to talk about how their family viewed Lucy's illness.

According to Lucy's mother, their family did not consider Lucy as ill and they preferred not to talk about it—in effect, equating silence with strength. She also told me that they have never talked to Lucy's older brothers about what cystic fibrosis means. Her mother voiced her doubts about this way of dealing with Lucy's illness but stated that this was the way she coped, to be strong and not talk about it. She then relayed a story about how one day Lucy became frustrated and said "I hate CF. I don't want to do this anymore." Lucy's mother said that she got angry with Lucy and said that she never wanted to hear her say that again and that there were others in worse situations than hers, relaying what those situations were.

Lucy's mother is not alone in struggling to explain CF to her child. Metaphor and analogy are often used to depict meaning and to help a child develop a philosophical stance. In this case, Lucy's mother seemed to be at a loss for words that would lend comprehensibility and meaning to an illness that was perhaps difficult to accept. At times parents of children with CF have difficulty finding suitable frameworks to give meaning to the experiences of illness, for themselves *and* their children (Jessup & Parkinson, 2010).

When such statements eluded them, many of the parents resorted to the there's-always-someone-worse-off scenario. Illustrating it with extremes of medical calamities, they calculated CF to be not quite so bad when grouped with being 'born without any bones in the fingers' (Stuart) or 'run over by a speedboat' (Liz). Literal analogies were used in a comparative interchange, as the substitutionary sifting of metaphor was momentarily abandoned and CF examined for its stark reality, albeit in comparison with another actuality, so that it was not the very worst one that could happen. (p. 360)

Lucy's mother shared that, although not talking about illness was the way *she* coped; she wondered whether silence and avoidance were helpful coping strategies for Lucy and her siblings. She also worried about what she would say if Lucy did have questions and lamented that most people with cystic fibrosis only live an average of 35 years. She wondered how she would answer the hard questions that Lucy might have while maintaining an appearance of strength and composure. Jessup and Parkinson (2010) speak of this unique dynamic between the parent and child with CF. Since parents are informed of their children's CF when the children are often too young to understand the long-term ramifications, parents are left with the responsibility for informing them as they develop and acquire growing realizations with each new illness crisis. This responsibility for informing children about their disease "engendered a diametrical opposition within their relationship, when the very ones who would want to endow life were left to frame its finiteness with their words, in a bizarre telling of the facts of life and death" (Jessup & Parkinson, 2010, p. 358).

For participants in Jessup and Parkinson's study, there remained a lingering fear that no matter how well the family adhered to treatment, CF was lurking in the background, ready to attack, thwarting continual counter moves in its unyielding destruction of the body. Sub-textual analysis of parental stories revealed a sense of failure in their efforts to keep their child alive.

Helping children to find meaning in difficult situations such as pain, suffering, and loss is one aspect of children's spirituality that adults find difficult because of a desire to protect them and the possibility that they will not be able to provide definitive

and comforting answers to children's existential questions. By avoiding engagement in discussion about the difficult to answer questions in life, children may learn not to ask such questions (Eaude, 2009). For Lucy's mother, not talking about illness may also have been way to forget, to keep illness hidden in the mundane aspects of daily life. Perhaps it provided a reprieve or sanctuary from the fear in an illness that can relentlessly ravage a young life.

As Lucy's family lived illness as an unspeakable narrative, a cloak of silence enveloped them and protected them from the harsh realities and fears of an uncertain future. Within this narrative, Lucy seemed to understand the need for silence about her illness.

Interviewer: So, if you had any worries or concerns or things like that, who would you go to?

Lucy: Ah, I would just probably try solving it all myself.

Interviewer: You wouldn't ask anybody or tell anybody.

Lucy: No

When asked, Lucy denied having any concerns or worries with regard to having cystic fibrosis, maintaining a stoic stance that mirrored that of her mother. For Lucy, perhaps silence was a way of living her illness that in some ways might be regarded as a source of strength. In her silence, there was a forgetfulness of CF—a closeting that kept it hidden like a well-worn coat sodden with rain. Damp and heavy, perhaps Lucy removes it so she can go about her day unencumbered. It is an ugly coat and she hates it but she has to wear it at times throughout the day to keep her warm because it is the only one she has. It is her life.

With the exception of treatments being a reminder of their condition, concerns about CF are not usually central in children's everyday lives. However, as they enter early adolescence their growing awareness of the disease and its manifestations often leads to philosophical questioning and a search for meaning in the illness experience. Along with this awareness, there may also be a sense of vulnerability and existential threat in their growing realizations that CF is not only bothersome but a threat to their very existence (Admi, 1996). Development of abstract thought and expanding cognitive understandings about death as the ultimate threat may leave many adolescents grappling with this conundrum as never before in their young lives. Anxiety about death is not only

a lingering specter in the everyday lives of seriously ill adolescents; it is also manifested in life contemplation among adolescents in general (Noppe & Noppe, 2004).

Although self-reliance in dealing with challenges of illness may have contributed to a sense of self-efficacy and independence, silence may have also made it more difficult for Lucy to develop meaning and purpose in illness since meaning making is often facilitated in conversations with others. For youth with CF, searching for meaning in illness by contemplating one's eventual mortality may enable them to realize personal growth and appreciate the positive impact CF has had on their lives (Jessup & Parkinson, 2010). Without this dialogue, a transformative illness narrative that integrates self and illness and self with others has less chance to emerge. Instead, living illness as unspeakable relegates illness to the shadows, a place of forgetfulness. In the midst of life threat to self or to one's child, a desire for forgetfulness is understandable.

Silence about illness may also contribute to the ill person blaming themselves for their condition or to feelings of embarrassment, frustration, or a sense of being unacceptable to others (Friedman, 2010). In keeping with Hay and Nye's (2006) concept of relational consciousness as central to spiritual development, other authors (Eaude, 2009; Holder et al., 2010) discuss the importance of finding meaning and connectedness through meeting and working through life's challenges and the salutary effects of spirituality and meaning making with relation to children's happiness and emotional well-being. Having said this, it is important to recognize that some people may prefer to abstain from honest conversations about illness, and this preference needs to be respected (Friedman, 2010). As Lucy's story continues in subsequent sections, illness as unspeakable is a theme that continues to appear in her daily interactions as she works through the challenges of her illness.

### **Matt (13 Years)**

Matt is a thirteen-year-old boy who has cancer and is an honor student who had just completed grade eight at the local junior high school. At the time of our first meeting, Matt was still receiving treatment and he had been diagnosed with cancer for one and a half years. He enjoys cooking, video games, sports, drawing, and hanging out with his friends. I met with Matt on three separate occasions, twice at the hospital and once at his home. Although his parents voiced an interest in staying during the first

interview, Matt's lack of response to some initial questions about important people in his life prompted them to leave, feeling that Matt might be more forthcoming in their absence. During our conversations, Matt often became quiet and hung his head in response to questions. After giving Matt time to think in silence about the questions, I would follow up with probes. He did not elaborate much when I asked probing questions, and he later told me that the questions were sometimes difficult to answer.

Interviewer: What about the way you look at life . . . Would you say you look at life any differently . . . now as opposed to before you got sick?

Matt: Yeah

Interviewer: Yeah? How is it different?

Matt: [Silent for about fifteen seconds]

Interviewer: You know a lot of people, when something happens in their life that's monumental, or big things, they sit down and think about things. So how has it changed for you?

Matt: [Silent for about seven seconds]

Although Matt disclosed that he looked at life differently since being diagnosed with cancer, he was unable to articulate how his view was different. Earlier in this interview, he said he was in the hospital for two weeks during the initial treatment for his cancer and relayed that this was a tough time for him. When asked what it was like, he once again had difficulty talking about the experience as he hung his head in silence. It later became known in the second interview (discussed in a later section) that Matt had experienced the death of a friend to the same disease while in hospital grappling with the uncertainty of his own diagnosis. Perhaps this loss prompted Matt to contemplate his own mortality and made this experience particularly difficult to discuss. Of all the distressing events experienced by preadolescent children with cancer, worry about death was the most frequently cited cause of emotional [and spiritual] suffering (Hedstrom, Haglund, Skolin, & von Essen, 2003). Losing a friend to the same disease also provokes fear in an adolescent in which contemplation of their own potential premature death often hinders their associated grief (Jessup & Parkinson, 2010).

Childhood cancer survivors have spoken of the indelible effects of illness on their lives. For the youth in Jessup and Parkinson's (2010) study, finding meaning in the illness experience was one of the recurring themes, along with a renewed appreciation of life and relationships and a resulting personal growth. Facing the death of friends and contemplating one's own mortality may also prompt adolescents to contemplate their

own survival and question their previously-held views of self and other (Jones, Parker-Raley, & Barczyk, 2011; Parry & Chesler, 2005).

While many childhood cancer survivors in the above studies revealed an awareness of their vulnerability and mortality, they also spoke of a resulting positive change in their spiritual philosophy or outlook on life because of it (Parry & Chesler, 2005). Paradoxically, although this existential uncertainty may have resulted in concern and even distress for some (Parry, 2003), findings suggest that the process of finding meaning and purpose in illness results in profound psychospiritual growth. This process not only results in greater understanding of illness, self, and other, but may also serve as a protective factor to mitigate vulnerability and contribute to long-term psychosocial well-being and resilience (Parry & Chesler, 2005).

Learning he had a life-threatening illness such as cancer, and having this be followed immediately by the loss of a friend to the same illness, Matt was left to contemplate what this meant for him. Although Matt was unable, during the first interview, to articulate his experience of his initial diagnosis and treatment experience, his silence was imbued with meaning. As he contemplated the question and reflected on his experiences, his silence seemed to be a struggle for words that could describe such life-changing events.

While finding the words to describe personal suffering is sometimes beyond one's grasp, once the words are found, the story may be too painful to tell. Sharing stories of suffering can be difficult because the suffering becomes real and objectified in the telling (Charmaz, 2002; Peltomaki, 2008). In asking questions about his illness, I may have been asking Matt to relive experiences that were fraught with recent loss and suffering. As he felt the pain in the remembering, Matt seemed to struggle to find words. Perhaps Matt's experience of being diagnosed with cancer was unspeakable because it made the vulnerability of illness all too apparent. As Matt suffered in silence, a story of illness as transformative may have been stifled. In this silence, he was alone in his struggle to find meaning and purpose in an illness that threatened the life that he knew. As Matt's story continues, further inquiries revealed deeper nuances of that suffering. Although initially inchoate, revelation of this suffering became an opportunity for reflection on life, death, and a sense of spiritual connection.

### **Quadeher (13 Years)**

Quadeher is a thirteen-year-old boy with cancer who had been diagnosed for about a year at the time of our meeting. He lives in a remote area and had just completed grade seven at the community school for children in grades kindergarten to twelve. He enjoys video games and reading. He also had a strong connection to his church community, attending weekly Sunday school and youth group and a yearly summer bible camp.

I met with Quadeher twice at the IWK Health Centre and once at his local hospital. His mother was present for the first interview and Quadeher and I met privately for the two subsequent interviews. Quadeher was a youth of very few words and did not offer grand elaborations or descriptive stories about his experiences. In his few words and by using body language, however, he was able to convey some underlying thoughts and feelings that spoke of the nature of his experiences of illness and how this related to his overall sense of being.

Interviewer: What was that like for you? You know, at thirteen years of age, that's a pretty big thing. What was that like when you first found out?

Quadeher: Scary

Interviewer: Yeah? Scary. What were you afraid of mostly?

Quadeher: What might happen?

Interviewer: What was going through your mind?

Quadeher: I can't really remember.

Interviewer: Mmm hmm, but it was scary. Mmm hmm. Did you think at all about the future and what the future might be like?

Quadeher: [Shrug]

Learning that he had cancer and starting the initial treatment was a scary time for Quadeher. He worried about what would happen and what this would mean for him. At first, Quadeher stated that he was unable to recall what he was most afraid of and what was going through his mind during the early days of his diagnosis and treatment. Given the significance of this event in his life, I wondered if he was truly unable to remember his initial thoughts and feelings or if putting these fears into words were just too difficult for him.

. . . when people suddenly lose a loved one or lie in a hospital in great pain, they may not so much become undone as become aroused

psychologically—prompted to look with the utmost intensity at their past life, their present condition, and their future prospects, if any. Under such circumstances, psychological themes connect almost imperceptibly, but quite vividly at moments, with a spiritual inwardness. (Coles, 1990, p. 101)

Quadeher's non-verbal shrug in lieu of his previous admission of fear about what would happen to him perhaps indicated his reluctance or inability to put his fears into words. Putting words to one's fears brings them into the light, forcing one to meet them head on. For some, voicing unspoken suffering may also serve to undermine the current views they may hold about their illness and potential recovery (Charmaz, 2002). Later in this interview, I asked Quadeher directly about his fears.

Interviewer: Did you ever worry that you wouldn't get better?

Quadeher: [Nods affirmative]

Interviewer: Mmm hmm . . . and what do you think about that? How are you feeling about that now?

Quadeher: That I was wrong.

When asked if he was concerned about not getting better, Quadeher responded with an affirmative nod. Although he was still unable to put words to his fears, his bodily response indicated confirmation of his concern for his life. Although the prognosis for childhood cancers are highly predictable overall, and chances of survival can be estimated, what is not predictable is the outcome for an individual. This can create uncertainty about one's potential for survival (Clunies-Ross & Lansdown, 1988).

As I thought about Quadeher's initial fear and uncertainty with regard to his illness, I wondered if he would have benefited from talking to someone about these unexpressed feelings.

Interviewer: Did you talk to anybody about how you were feeling when you were up here?

Quadeher: No

Interviewer: Would it have helped if you were able to talk to somebody?

Quadeher: [Nods affirmative]

Interviewer: Yeah? Because you had a lot of things going on in your mind and you know what Quadeher?

Quadeher: Hmm?

Interviewer: That's common for young people to hold it all inside and worry and fret, you know, and not know who to talk to, yeah. Do you feel that it would help to talk to anybody now about things?



Quadeher: [Shakes his head 'no']

Similar to adults, children view cancer negatively, often associating it with death, even before having any direct experience with it (Knighting, Rowa-Dewar, Malcom, Kearney, & Gibson, 2010; Oakley, Bendelow, Barnes, Buchanan, & Husain, 1995). As Quadeher voiced his early feelings of uncertainty and fear, he said that it would have helped to talk to someone about it at the time. At the time of the interviews however, Quadeher had made it through the initial stages of diagnosis and treatment and stated that he was no longer worried about not getting better. Although his previous need to talk seems to have gone unrecognized, perhaps now that he was in remission and coping with the effects of his illness and treatment, thoughts and fears of his future well-being were no longer so pressing. Perhaps he trusted that he would survive.

Quadeher's inability or reluctance to elaborate on illness and its meanings echoes the *illness as unspeakable narrative* in Matt and Lucy's stories. Although the circumstances are different, in their silence, these children are cut off from dialogue that might allow them to create meaning from their circumstances, meaning that might ease suffering. This may prevent them from developing a narrative that integrates illness into their lives in a way that promotes a sense of coherence or unity that has been found to be salutogenic to health and well-being (Antonovsky, 1979).

### **Illness as Suffering**

#### **Jake (11 Years)**

Jake was an eleven-year-old boy with cancer who lived at home with his parents. He was the youngest and the only child living at home. At the time of our meeting, he was battling a recurrence of his cancer and was having tests to determine his response to the latest round of chemotherapy. He had had numerous treatments and surgeries prior to this and needed a wheelchair to get around. Both of his parents were present with Jake for his hospital appointments. However, his mother took the lead in the discussion about the study and in the initiation of consent. Jake seemed to have a tentative interest in participating in our conversation when we sat down to initiate the consent process. As he remained engrossed in playing his video game, he voiced his reluctance to stop. Focused on the game, intent on winning, he assured me that he could listen and play at the same time.

Throughout our conversation, Jake remained focused on drawing and painting pictures of Pokémon, at times using them to guide the conversation. At certain points, he even expressed his anger and frustration as he used the pencils and paintbrushes with force against the canvas and paper. In retrospect, after talking with Jake's mother, it became clear that Jake experienced difficulty articulating his thoughts and feelings. She said that he was a very spiritual person and that he did have deep thoughts and feelings that he might be better able to express through characters or situations. Unfortunately, there was not an opportunity to meet with Jake a second time because the progression of his illness precluded his continued participation and eventually led to his death prior to the completion of this study.

When asked what it was like being ill, Jake readily described his thoughts and feelings.

Interviewer: What has it been like for you being sick?

Jake: Horrible

Interviewer: Horrible. Tell me about that

Jake: Throwing up, stuff like that. You can't walk. Hurting, pain—occasionally agony right after surgery

Jake described his experience of illness as being horrible. The word horrible originates from the Latin root "horribilis" which means "terrible, fearful, [or] dreadful" and from "horrere" meaning to "bristle with fear" or "shudder" (Harper, 2001-2013). Jake's description of illness encompasses more than a physical suffering. His words reflect fear, fear perhaps of the future, or even of the present. Given that he was at the hospital for tests to determine his response to the latest treatment, I wondered what he was thinking. His body no longer looked or behaved as it should, and perhaps this led him to contemplate his losses and wonder about his future.

Jake also described his experience of surgery as agony. Agony is a word that originates from the Late Latin and Greek word "agonia" meaning "a (mental) struggle for victory," usually in preparation for games of combat in which one's life is at stake. Later in the early 14<sup>th</sup> century, the word came to mean, "mental suffering (especially that of Christ in the Garden of Gethsemane)." During the same era in Old French, the word agony was rooted in the words "agonie" or "agoine" meaning "anguish," "terror," or "death agony" (Harper, 2001-2013). Interestingly, both biblical and non-biblical uses of

the word agony denote a mental anguish that is felt in the contemplation of the end of one's own life.

Children with advanced illness often experience suffering that affects not only the physical, but also the psychological, social, and spiritual domains of life (Foster, Bell, & Gilmer, 2012). Peltomaki (2008) also speaks of this profound and all-encompassing suffering but refers to it as "affliction" to denote that its effect on the whole of one's being "leaves no area of life unscathed" (p. 223). In addition to the physical and emotional anguish in Jake's expressions, I also wondered if he was experiencing existential or spiritual distress that remained unspoken as he reflected on the meaning of his progressing illness. Philosophically, suffering is implicated with spiritual pain. Suffering is felt when one perceives an existential threat and an accompanying sense of not having the resources to deal with it (Krikorian & Limonero, 2012). If one is unable to find purpose and meaning in suffering, this further adds to a lack of coherence, and perhaps a spiritual void that deepens the suffering felt.

Perhaps the experiences of illness were horrible for Jake not only because of the throwing up, his inability to walk, and the pain that it caused but also because of what it meant in relation to his being able to survive and live a life of quality. This existential or spiritual suffering was not articulated perhaps because it lay hidden in questions not asked and not answered. While discussion of such weighty life questions is difficult for children at the best of times, tentativeness in the research relationship may also have contributed to Jake's inability to share such deeply held meanings and questions.

As Jake sat in his wheelchair, concentrating on his drawing, he avoided eye contact and displayed an inwardness that was penetrated only when issues of meaning arose. At times, there was an undercurrent of anger and frustration in his tone that would flair when asked questions he found difficult to answer. When asked what it was like to have cancer, he was able to articulate his thoughts and feelings using descriptive words. He responded readily to these questions, albeit briefly, and was open to talking about certain aspects of his illness if asked about it directly.

Interviewer: So what happened here? [Referring to a scar as I touched it gently]

Jake: Huh?

Interviewer: What happened right there?

Jake: Surgery, second cancer  
Interviewer: Yeah?  
Jake: Mmm hmm  
Interviewer: When was that now?  
Jake: [Writing names on paper] not sure.

The scar was a visible sign of the history of his illness and related to the agony of his experiences of surgery. It also signified the return of his cancer, a “second cancer” that resulted in further treatment and diminished chances of survival. He was willing to disclose the meaning of the scar in relation to the recurrence of his cancer, along with his uncertainty about the timing of this event. Questioning the *timing* of the recurrence was irrelevant to Jake. What seemed to be more significant were the recurrence of the cancer and the meaning of this event with relation to his present and future life. Given that, Jake was once again awaiting results of tests that would determine the effectiveness of the latest treatments in keeping his cancer at bay; I wondered what effect this was having on his emotional and spiritual well-being.

This waiting is one of the ‘sufferings in suffering,’ partly because there are so many uncertainties about what lies ahead: ‘How long will this go on?’, ‘Can I endure it?’, ‘What if I can’t?’, ‘Who will come to stay with me?’, and ‘It’s been so long—does God not hear me?’ For the afflicted, the period of waiting is often perceived as the most difficult part of the journey. Waiting is not desirable or easy to accept. It offers its own unique agonies that cannot be dismissed or downplayed (e.g. as the calm before the storm). (Peltomaki, 2008, p. 226)

In therapeutic sessions with adult family members of a man who was gravely ill, Wright (2008) described the suffering that culminates in waiting in the midst of uncertainty. She also recognized that the intensity of a family’s suffering might be magnified by their inability to find meaning in the experience. This leads me to wonder. If these adults were experiencing profound suffering in their witnessing and waiting through the end-stage illness of a loved one; I wonder how children make sense of their own illness-related suffering and uncertainty?

Before the beginning of this interview, and prior to learning that Jake was dying, his mom revealed that Jake often listened to the conversations of others when the adults around him were unaware of his attentiveness.

Interviewer: You know what? [With a laugh] I remember when your parents were here they were saying something about how you hear things, when they think you're not listening.

Jake: Yeah

Interviewer: So, what kinds of things do you hear?

Jake: Ah . . . stuff

Interviewer: Can you remember anything?

Jake: Not really.

Interviewer: No? Is it about you?

Jake: Not as well.

Interviewer: What was that?

Jake: I'm not sure.

Jake admitted that he listened to the conversations of others when they were not aware he was there. Keenly attentive to the family discussions taking place around him, it is possible he was looking for information that would help him to make sense of what was happening to him. Although Jake could not really remember the specifics of what he heard, or chose not to share them, when asked if conversations were about him he responded "not as well." Maybe he suspected that he was not as well as he had been but he was not sure and was unable to articulate his fears.

Children who are nearing death are often aware of their condition long before being told. They may also participate in a "conspiracy of silence" that leads to avoidance of the subject of dying in order to protect their parents from emotional pain and suffering (Ball, Bindler, & Cowen, 2010; Kamper et al., 2010). As Jake felt his pain increasing and his mobility decreasing, he remained silent, perhaps looking for clues to what this might mean for him and his future.

Without open communication about illness, children often form ideas about what is happening to them that might be more frightening than they would be if given age-appropriate information, guidance, and support (Ball et al., 2010; Higgins, 1999). As Jake noted the deterioration of his body and anticipated the results of the medical evaluation of his progress, he was likely worrying in silence and wondering about the outcome. He may also have been protecting others by not voicing his silent fears, as he searched for confirmation within snippets of conversations that kept him on alert for clues to his well-being.

Jake's story is one of immense suffering. As he endured the horrible and agonizing effects of his illness and treatments, he experienced a deep anguish. As

cancer's relentless effects burdened him with vomiting, pain, and a loss of mobility, he found voice in his anger as his fears lay hidden. "Children with a chronic illness who are facing premature death are likely to experience some degree of spiritual distress" (Hart & Schneider, 1997)—a state of being in which anger and fear are common signs (Fulton & Murphy Moore, 1995). Perhaps this was the only way Jake could express his suffering as he endured the pain and lived the unpredictability of his illness.

**Bob (9 Years)**

Bob is a nine-year-old boy who was diagnosed with cancer at the age of five. When I first met Bob, he had been finished treatment for one year. Bob enjoys reading, video games, and amusing television shows, often preferring indoor activities to playing outside. He is a successful student who received an "A" in most school subjects and who felt disappointed with anything less. He also had a good sense of humor and at times found pleasure in goading his parents.

Although it had been a year since he completed his three years of treatment for his cancer he could still recall his experiences of learning of his diagnosis and beginning treatment. While he reported a lack of understanding of what was happening to him at first, he remembered vividly when it was, where he was, and how it all started. He recalled that he was visiting his grandparents at Christmastime when he was five-years-old, and when he got up to leave, he was unable to walk on his foot. At first, he understood that there was something in his blood and that it was in his heel. Soon thereafter, he learned that he had cancer that would require three long years of treatment.

Prior to the second interview, Bob was asked to draw some pictures about his experiences of being diagnosed with cancer. Through his drawings, he was able to elaborate on how he felt as he learned of his diagnosis and attempted to make sense of what was happening to him.



**Figure 5.1: How I Felt**

Bob: This one is how I felt.

Interviewer: Wow!

Bob: The emotions of how I felt in the hospital.

Interviewer: Can you describe these to me?

Bob: Sad, bored, scared, I don't understand, unhappy. That one's almost the same as that one . . . shock. That one's just bored. That's that.

Interviewer: Wow . . . I like what you did there . . . and what's that one?

Bob: Surprised.

Initially upon hearing the diagnosis of cancer, Bob was surprised and shocked by the news. Without warning, cancer appeared as an enemy, invading Bob's body. Unforeseen and insidious, this foreign invader waged war within his blood. As a boy of five years, he did not fully understand what was happening to him. Perhaps he also wondered what this would mean for him. When first asked what it was like for him when he learned he had cancer, he said it was "a little bit scary." The shock and surprise of learning of his diagnosis was laced with fear of the unknown. Inundated by invasive tests and treatments he was confined to a space and body that was under attack, preventing him from engaging in his usual daily activities. Bob also described his initial experience of hospitalization and illness as tiring.

Bob: When I had to stay overnight for a while, I was kind of annoyed because I wasn't allowed to lie on my stomach. It was uncomfortable to lie on my side and I don't like sleeping on my back because it makes my back sore.

Treatments became annoying after a while as illness wreaked havoc on an unwilling body. Bob did not like what was happening to him and he had little control over what the illness and others were doing to him. With a needle protruding from his chest he could not lie on his stomach, while lying on his side and back also caused him discomfort.

For Bob, cancer struck unexpectedly. His body was being attacked and manipulated from within, manifested in restrictions in movement and freedom. Gadow (1980, 1982) explained that when illness strikes, there is a disruption of the lived body in which the body becomes alien or “other” to the self and where healthcare practices often objectify the body as a thing to be manipulated or fixed. It is also a time when the body may constrain and limit one’s actions and hence disrupt previously held meanings of relationships with self, other, and world. Although this work is based on adult illness experiences, it may also be relevant for children.

This experience of disconnection where one views the self or others as alien or object has been described as *disembodiment* (Duden, 1993; Goldberg, 2005). Perhaps this can also be viewed as disembodiment of spirit, a disconnection of self that longs for meaning and coherence. Coherence engenders a sense of sticking together (Harper, 2001-2013). Perhaps a sense of coherence then is a feeling of being whole or healed—a feeling of being unified or “at one” with oneself and others. This search for meaning, purpose, and connectedness is perhaps one’s spirit in action, seeking a place to feel at home.

Bob also talked about his fear of having surgery to have a port-a-cath put in. The thought of being put to sleep and having something implanted in his body was frightening. Knowing this would be where dreaded needles would pierce his body, he anticipated the experience with trepidation.

Interviewer: So what were you most frightened about?

Bob: Needles . . . Most of the time I would have to have people restrain me

Interviewer: What was that like?

Bob: Annoying

Interviewer: That must have been tough.

Bob: Well I wouldn’t stop squirming.

Interviewer: It’s hard to stay still.

Bob: Well I don’t like needles so I just squirm so I don’t have to do it.



For Bob, the most frightening part about having cancer was the needles. As he lay there tired, having already lost part of his mobility, he was subjected to painful needles and was infused with medications that made him feel ill. As his treatments continued, Bob had to endure the ongoing insults to his body. When faced with the inevitable need for needles, Bob defended himself by squirming in an attempt to slip from the grasp of those who restrained him. Motivated by fear, he used all the strength his body contained to escape being pinned down and poked. He had little choice in these situations and so he opted to use his body in the attempt to regain control, hoping to avoid the dreaded needles all together. Although techniques for assisting children to cope with painful procedures have improved over time, this remains one of the most frightening aspects of healthcare for young children that can often lead to a fear of needles and other medical treatment that lasts well into adulthood (Ball et al., 2010).

In addition to this initial hospitalization being a scary time, Bob also found it to be a bit boring. Boring, a word that originated in the mid-15<sup>th</sup> century signifies the “action of piercing,” while later in 1840 it came to mean “wearying, causing ennui.” Interestingly, the word ennui is rooted in the Old French word ennui, meaning “annoyance” (Harper, 2001-2013), adding further understanding of the feelings of piercing irritation that Bob felt in his situational confinement. Initially, with a needle in his arm and strapping to hold it still, he was unable to use his arm making it impossible even to read a book. Unable to walk, read a book, or even sleep sometimes, time no doubt passed slowly.

Although Bob was only five years old at the time of his diagnosis, the vivid recall of his experience speaks to the significance this event has had in his life. Shocked and frightened by this alien invader of his body, he struggled to understand what this would mean for him. Cancer not only challenged his taken for granted control of his own body and sense of self, it had also disrupted the flow of his life and relationships. For preschool and young school-aged children, the greatest fears related to illness and hospitalizations are being alone, being abandoned or left in the dark, loss of control of body or emotions, and of bodily injury and mutilation. In addition, children of this age sometimes view illness as a punishment and harbor feelings of guilt and remorse (Ball et al., 2010).

Perhaps Bob's sense of self and security of self in the world had been shattered, and hence his very being was threatened. Furthermore, those he relied on to care for him were sometimes complicit in the acts that contributed to this threat, such as in the restraint required to administer the dreaded needles. Perhaps Bob longed for a "hospitable space" (Kimes Myers, 1997), a safe space that gave him the sense of being at home. Given that he was only five-years-old at the time of his diagnosis, I wonder how he might find meaning and purpose in his illness and suffering. As Bob's story unfolded, there were clues to how he may have transcended his felt sense of boredom, fear, and insecurity.

### **Tony (10 Years)**

Tony is a ten-year-old boy who has cystic fibrosis and lives with his adoptive family. Tony's family affiliates with a religious community and attends church on most Sundays. Tony claimed to have many friends and said that playing was a very important part of his life. He is also a very animated boy who used sound effects and movement when describing and acting out his experiences of play. I met with Tony on three separate occasions at his home, and during the first interview, Tony's father was present and was able to give some background information about Tony's early childhood experiences and illness. During the second two interviews, I met with Tony alone while his mother was present in an adjoining room.

Of all the children interviewed, Tony expressed the least discontent with the demands of his treatment and illness. Although most aspects of illness were not troubling to Tony, he did not like taking his vitamins because they were "gross" and said that he did not like the "evil blood work" and that blood work was "not friendly." He also lamented that the "paddles" that were used for his physiotherapy were "painful." Staying healthy was important to Tony, and although he would comply when it was time to take his pills or do his masks and physiotherapy, he often became distracted by things of interest around him. This would lead to regular reminders to stay on task and would sometimes lead to the removal of things of interest, like turning off the television, so that Tony could concentrate on completing his therapy.

According to Tony's father, he had never had to stay in hospital and his illness had been well controlled. However, there were aspects of his illness that manifested as

bodily restrictions, sometimes preventing him from fully participating in activities with his friends. Tony described some of the aspects of his illness that he found tough to get through.

Interviewer: What else [is tough about having CF]?

Tony: Mmm . . . Nose bleeds

Interviewer: Nosebleeds?

Tony: Because I'm getting nose bleeds half the time

Interviewer: Mmm hmm . . . and that's tough, yeah

Tony: Having to stop and drink Gatorade when I'm running

Interviewer: Mmm hmm, does it affect your running?

Tony: No, but when I have to cough, I have to stop. I can't cough on the run.

The physical manifestations of Tony's illness resulted in a body that betrayed his intentions. Nosebleeds that happened "half the time" occurred with enough frequency to be bothersome to Tony, making it necessary to stop all activities in order to attend to them. The spilling of blood can also be alarming, creating an occasion for personal fright and public spectacle. While exploring children's experiences with CF, Jessup and Parkinson (2010) found that, many young people felt their bodies did not belong to them at times. In watershed moments, in which the body became informant, the children were reminded of the life-threatening aspect of their illness. One of the participants in their study described his first experience with nosebleeds. "I remember thinking: 'Oh, shit. Yes, I am sick.' I remember being told that I was going to be lucky to be seeing the next couple of years, when I was about 16" (p. 359). It is the contemplation of the meaning of these frequent nosebleeds and their resulting restrictions on breathing that add to alarm and uncertainty.

Tony also recognized that he was quite a bit smaller than the rest of his peers. Being smaller than peers is a common issue for children with CF that becomes accentuated as they enter puberty. This growing visible discrepancy with their peers has the potential to undermine children's self-esteem, social support, and the process of identity formation (Jessup & Parkinson, 2010). Keeping up with his friends was a struggle for Tony when cystic fibrosis resulted in smaller stature, nosebleeds, and the limited capacity of his lungs that forced him to a halt. Racking coughs or nosebleeds stopped him in his tracks as he struggled to regain his equilibrium. As he fell behind, he

watched his healthy peers continue without impediment. His body betrayed him, heralding the restrictions and unpredictability of his illness.

Despite the differences between the illness trajectories and treatments associated with cancer and cystic fibrosis, all of the children interviewed expressed feelings about illness interrupting the flow of their daily lives and relationships. In addition to a loss of control of their bodies, there was a concomitant fear and uncertainty about what this meant with regard to their well-being. These threats to self and relationships are inextricably tied to spiritual wondering in that they prompt us to reflect on life and living in an attempt to discover meaning and purpose in the challenges we face (Faull & Hills, 2006). Illness and suffering present opportunities to explore the spiritual, find personal meaning, and discover plausible answers to existential questions that may serve to sustain us as future life crises arise (Canda, 2001; Faull & Hills, 2006; Parry, 2003; Parry & Chesler, 2005).

### **Illness as Intrusion on Time and Freedom**

In addition to physical and emotional impacts of illness, many of the children expressed their annoyance with the restrictions and impositions of illness and how being ill or its treatment resulted in their missing many meaningful and pleasurable activities in their daily lives. Experiencing life through a body that betrayed their intentions, the children in this study searched for ways to overcome the restrictions on body, time, and freedom. In managing illness, they sought ways to exert their will and regain some control in balancing responsibility for health with engagement in normal life activities.

#### **Crackle (10 Years)**

Crackle is a ten-year-old boy with cystic fibrosis who lives in a rural community. Despite having cystic fibrosis, Crackle described himself as being a “really healthy” person and displayed a very positive outlook on life. I met with Crackle on three separate occasions, twice at his home and once at the hospital, and found that he was quite eager to share his stories and was comfortable answering questions about himself and his experiences. He was also a straight “A” student with a creative mind and an artistic hand and displayed confidence in his many talents and abilities. He claimed to have many friends with whom he got along and he loved to play outdoors, getting immense pleasure from playing soccer—his favorite sport.

Although Crackle viewed himself as healthy, he described his experience of having cystic fibrosis and the burden of treatment with regard to its intrusion on his time.

Interviewer: So you've had cystic fibrosis since you were born right?

Crackle: [Nods affirmative]

Interviewer: And what's that like?

Crackle: It's kind of annoying most of the time because if I'm doing something really fun, 'Crackle, time to do your mask' [Referring to his father calling him to have his mask] 'Oh come on . . . okay' [Crackle relenting] 'Time to do your physio' [Referring to his father talking]. I sit down. 'Okay, time to go to bed' [Referring to Dad talking again].

Eahhhh. [Sound of exasperation].

Crackle described his treatments as being annoying most of the time denoting his feelings of irritation, displeasure, and distaste. Although the treatments have been part of his daily routine growing up, they were often seen as an interruption to the flow of his life. In essence, treatments interfered with those aspects of life that he found most meaningful and pleasurable—aspects of life that animated him.

Crackle also made reference to the reminding that was needed for him to attend to his treatments. This reminding was not only a signifier of the ever-present nature of his illness but was also a repeated message from his father about his shared responsibility for maintaining his health. This added responsibility separated him from friends and activities that were so important to his development and deprived him of continuing in the activities that brought him so much happiness. The spiritual is embedded in the meanings children attach to events, activities, objects, and relationships that add quality to life and make life worth living (Eaude, 2009). This is also the process of finding meaning and purpose with relation to one's being while reflecting on daily life.

Although both Crackle and his father agreed that he did not complain very much about having to do his treatments, they also agreed that Crackle procrastinated sometimes, indicating his reluctance to give up what he was doing in order to do his masks and physiotherapy. Knowing that there are only so many hours in a day, Crackle asserted his will by attempting to borrow time in order to spend it in ways that were meaningful to him—ways that renewed his energy to maintain the fight. Unfortunately, this procrastination only led to tension within the relationship between Crackle and his father.

When asked about how treatments affected other parts of his day, Crackle explained the difficulties with getting ready for school in the morning. He explained that for the last two mornings they were late because in addition to getting ready, he had to do his mask and positive expiratory pressure exercises (PEP). It was an adjustment since starting back to school after the summer holidays and Crackle was expected to move quickly in the morning in order to get ready and complete his treatments in time for school. Any procrastination or wasting of time resulted in his father getting mad at him for being late.

As Crackle described a usual day at home there was an indication of how treatments were viewed with regard to lived time and his relationship with his father.

Interviewer: What's a usual day at home for you?

Crackle: Usually on weekends when I don't have to go to my Mom's, usually it's bed, sleep in till nine, maybe ten sometimes. Then I wake up and then play a little bit. Then Dad gets mad at me and says to take my mask . . . And then I do it. Then we might do something later on, then he'll ask me, 'Did you have your afternoon mask?' and I might say, 'ah, yeah' [when he hadn't actually done it]

Dad: And I get mad at you again.

Crackle: And then I'll have it, and then I usually play a lot. Then we might go out shopping, and then when we come back . . .

Dad: Dad gets mad again. Say it again.

Crackle: No. We usually play video. We might watch a movie or watch a show together, and then when my Dad goes outside, it's like nine-thirty, he tells me to have my mask. Then he comes back in and I'm just starting it—and guess what happens.

Dad: I get mad.

Crackle: [Laugh] Yuh, and I finish and he does my physio and we get to stay up later because it's the weekend and then I can't fall asleep until twelve, and yeah.

When describing a typical weekend day, Crackle talked about the pleasurable activities such as playing or watching movies or television that were interspersed with reminders from his father to do his treatments. Crackle's father would often get mad at him for his lack of follow through when he was told to do his mask and PEP, and Crackle would procrastinate until his father's anger spurred him into action.

Crackle's desire to be free and play was pierced by the interruptions that heralded the responsibilities of his illness. Although he procrastinated at times, Crackle learned to comply without complaining. Within this compliance, there was a sense of acquiescence

or a “silent consent” (Harper, 2001-2013) that was implicit in Crackle’s adherence to his treatment regime. Unfortunately, the issue of adherence to CF treatment can become an even greater struggle as adolescents strive for increasing independence from parents and take on more of the responsibility for managing their health (Jessup & Parkinson, 2010; Taylor et al., 2010).

### **Lucy (13 Years)**

Lucy also described how her treatments interfered with daily life and with activities that gave her life meaning.

Interviewer: What is it like to have CF at thirteen?

Lucy: It gets annoying after a while . . . If I went on a sleep over, I have to come home and get my stuff . . . It’s annoying when you have to keep coming home. And the next morning you have to be home by dinnertime. You don’t have time the next day to sleep in because you stay up really late and you end up sleeping in longer and you don’t get to do anything that much when you wake up . . . When I have to get my aerosol and my physio I don’t really like it much cause it takes me away from things.

Like Crackle, Lucy resented being pulled away from activities that were fun. She missed out on times with her friends and was robbed of the shared experiences that gave her a sense of belonging in a peer group. Treatments were viewed as an annoyance and a restriction on freedom, taking Lucy away from the things she enjoyed most in life. Although there was little discussion within her family about her illness and what it meant, the illness was not silent in Lucy’s life. It called to her, reminding her of her need to attend to it. It pulled at her and confined her in its grasp as it devoured precious time.

Lucy stated that if she missed her aerosols and treatments, she would have to “fight off a cough.” This was one of the other challenges she faced with regard to her illness that she experienced as “not [being] fun.” While the treatments interfered with her fun at times, not doing her treatments resulted in exacerbations of her illness that were not fun either. She understood that if she was unable to fight off a cough, she would have to take pills for a couple of weeks and that this would make her better until she missed her treatments again. She also understood that not doing her treatments would likely result in hospitalization that, once again, was described as “not very fun.” However, she viewed these exacerbations as fixable and as temporary setbacks that could be overcome.

Exacerbations of illness become harbingers of its presence and a potential threat to being, serving “as a reminder that CF does not go away. It is not grown out of, but

rather grown into, as increasing time correlates with exacerbating signs” (Jessup & Parkinson, 2010, p. 359). However, despite knowledge that adherence to treatment schedules can reduce the risk of complications, Lucy chose to assert her will in the attempt to regain greater control over her time and her life. For Lucy, managing her illness with relation to time became a balancing act. In order to buy time and prevent her treatments from interfering with valued activities, she paid the price with interest when exacerbations of her illness stole her fun once again. Like Crackle, Lucy’s resistance to these calls to attend to her illness resulted in tensions between her and her parents.

Lucy: If we’re doing something and we’re getting ready to go to bed, my dad, or my mom hollers out and says that I have to get on my aerosol. Then I say, ‘but I’m making my bed,’ and they say ‘well you can make your bed while you’re doing your physio and aerosol’ . . . and it gets really annoying. . . . Or I’m playing a board game and I said ‘just wait a few minutes’ or ten minutes or whatever, and they say ‘can’t you do it while you’re on your aerosol?’ Then I play around and say no, and then they’re like ‘yes you can’ and they tell me to get on it. My dad kind of gets mad when I don’t want to get on it and I say no. Then he’s like, ‘I’m not asking you; I’m telling you.’

Interviewer: Mmm hmm, and so then what do you do?

Lucy: I get mad and then I start slamming around and everything . . . and [my father is] like ‘if you don’t wipe away your attitude then your friend is going to have to go home and you’re going to have to go to bed as soon as you’re done your aerosol and stuff.’ Then I kind of calm down.

In defying calls to attend to her health, Lucy attempted to assert some control and postpone the enforced interruptions of her treatments. She did not want to don the mask in the presence of her friend because this was a symbol of being different, the antithesis of fun and the free-flowing experience of play. In being forced to comply, Lucy did not consent quietly. She expressed her anger and frustration by “slamming around,” a symbolic gesture of her self-determination and the resentment and frustration she felt toward her disease and her parents.

### **Amy (13 Years)**

Like Lucy and Crackle, one of the repeated challenges Amy encountered with her illness was adherence to the demanding and time consuming treatment regime. As she described a typical day and her feelings with regard to the life disruptions imposed by her illness, we get a glimpse of how the burdens of treatment affected her well-being and how she dealt with this on a daily basis.



Amy: Well, I usually get up and have breakfast, and get dressed and ready for the day. Then, around ten or eleven, Mom will usually tell me to do my mask. It's usually a little fight to do it. It's not that I don't want to do it. I know I have to but I hate to do it. It just kind of bothers me. But in the end I do it and then I go on with my day... Sometimes I might be ready to go out with my friend and then my mom will come out and say 'Did you do your mask?' or 'Don't forget to do your mask,' and I'm like 'Aaah, now I'll have to wait longer.' But then, I'll just get up and get it ready, and just do it right away. I'll even forget I have it on and it will be like twenty minutes gone by and it'll be done.

Even though Amy knew that her treatments were necessary to maintain her health, like the others, she still resisted doing them at times. This struggle to break free from her illness also led to fighting with her mother who was there to help remind her of her responsibilities. She grappled with this tension because on the one hand she was very aware of how ill she could become if she neglected to do her treatments. On the other hand, she felt like she was missing out on life because of them.

In the account of her experiences of having to adhere to her daily treatments, Amy also revealed feelings of resignation. Because she was unwilling to give up the fight against her disease, she knew that she must give up in the fight against doing her treatments. While treatments pinned her down, as Amy described in a later section, they also ensured protection from illness complications that would result in further limitations on her freedom and quality of life. This inner battle became one of dueling intentions – wanting to be healthy while also wanting to live her life unfettered by the constant reminders of the challenges and responsibilities of her illness.

Despite her frustration with the life limitations her treatments imposed, Amy also resigned herself to the fact that if she just did her treatments they would be over quickly. She could then forget about her disease and its reminders and get on with having fun. This way of framing time and the situation enabled her to see the treatments as tolerable. Distracting herself was also a way of coping with missed time, enabling her to forget about the fact that she was doing her treatment while helping her to refocus her attention away from the fun she might be missing.

### **Bob (9 Years)**

Bob also framed his illness in relation to time. Time spent in hospital was described as boring. When he was able, Bob passed the time sleeping, getting some needed rest, affording him a temporary escape from illness. Time seemed to pass so slowly when he was confined and not able to participate in his usual activities. When asked how he got through the initial diagnosis and treatment period Bob said that he watched the fish in an aquarium outside his room. As he focused on the movement and color of life under water, he was soothed and distracted from his fearful and boring confinement. Perhaps by engaging with the beauty in nature, Bob was able to transcend his pain and suffering. Appreciating the beauty in nature has the potential to draw one away from a focus on the self and may lead to a sense of self as being part of something bigger (Chan, Chan, & Ng, 2006).

Bob continued to endure the ebb and flow of his three years of treatment, and at the time of these interviews, Bob had been finished his treatment for approximately a year.

Interviewer: So what about now? You're all done treatment. So what does that mean for you?

Bob: I get to have more time at home. I get to play video games more often and I actually get to play my video games because when I was in the hospital, I wasn't allowed to choose what I wanted to play. My dad would go down and choose what he wanted to.

Finishing treatment had significance to Bob since it was a milestone in his movement away from illness. He was now able to spend more time at home playing and choosing the games he wanted to play. He was free to be a child, to spend more time in preferred play, released from the intrusions of the body and time restraints of his illness. Although Bob was finished his treatment, he was still required to return to the hospital for follow-up. As he moved further away from completing his treatment, his follow-up appointments would become less and less frequent.

As Bob questioned his mother about how many more years of follow-up were needed, and how long he now had between appointments, he underestimated the number of years of follow-up needed and overestimated the time between appointments. As he attempted to stretch the limits of time to his advantage, he was faced with the indelible

schedule that would dictate his connection to the hospital and his illness. Although he felt that going to the hospital every two months was not as bad as having to go in all the time, he longed for the time when he no longer had to face the rigors of testing and investigations of his body. When asked what follow-up meant, Bob stated that he had to have a blood test. For him this was the dreaded aspect of his follow-up appointments, to be poked and to be pinned down during which any bodily resistance would be futile.

The meanings these children attached to their illnesses often related to challenges, such as restrictions on time and freedom, fear and pain, and a lack of control and limitations of the body. Intertwined with these meanings were the social aspects of illness that resulted in feelings of otherness. Feeling separated and different from others and being unable to express feelings and unspoken fears also contributed to isolation in illness.

These meanings have significance with regard to the spiritual in that one's core sense of self and self in relation can be disrupted by losses experienced because of illness. Having missed out on many normal experiences of childhood, cancer survivors often struggle to find benefits and meaning in the experience and have difficulty forming a new identity that integrates the illness experience with being a survivor (Jones et al., 2011). Conversely, illness and its meanings also have the potential to elicit reflection on life and living, providing opportunities for spiritual growth.

We perceive ourselves to be healthy when we have a sense of the core self or the essence of self as constant and continuing to exist despite physical, mental, and social limitations (Faull & Hills, 2006). When ill health disrupts continuity and meaning in existence, opportunities for transformation through learning and growth are possible. Through acceptance of loss and integration of the changed self through reflection and alignment with personal beliefs and values, we are able to nurture the core or spiritual self. This ultimately leads to "deeper, more meaningful relationships and an expanded self-knowledge, based on a comprehension of one's identity, place, meaning and purpose in life" (p. 730). While referring to the meanings of illness expressed so far, and the associated connection to the relational and to the spiritual, the next section will add to these understandings as they relate to identity and relationships with peers. Spirituality is deeply rooted in identity and in our understanding of who we are (Eaude, 2009), and it is

the relational aspect of self that is most relevant to a spiritual and existential understanding of personal identity (Webster, 2005).

### **Illness as Isolation**

One of the central aspects of childhood spirituality is a search for meaning in life's existential questions, such as Who am I? Where do I fit in? Why am I here? These questions relate to the adolescent's identity, place, and purpose (Eaude, 2003, 2009; Hyde, 2008). Establishing a sense of identity is an important task for children, especially as they enter their teen years.

The transition from adolescence to young adulthood is an especially significant phase in the development of human identity. A fundamental challenge of mythmaking in adolescence and young adulthood is to formulate personally meaningful answers to ideological questions so that one's identity can be built on a stable foundation. (McAdams, 1993, p. 36)

Although parents continue to play an integral role in this identity formation, peers become more important than in younger years as independence grows and as children search for belonging in social groups outside family circles. Peer groups provide a sense of sameness for the child, one in which their shared journey toward adulthood provides grounds for forming a sense of identity and meaning (Ball et al., 2010; Crawford, O'Dougherty Wright, & Masten, 2006). Adhering to social norms and appearances of being the same facilitates a sense of belonging to these peer groups, while outward differences may pose a threat to that sense of belonging (Ball et al. 2010; Christian & D'Aura, 1997; Fagerskiold & Mattsson, 2010; Jones et al., 2011; Williams, Mukhopadhyay, Dowell, & Coyle, 2007). How children view themselves as individuals in the context of illness and social connections and disconnections affects their growing spirituality as they navigate the social sphere and search for a place that affirms them and welcomes them as members of worth.

### **Amy (13 Years)**

Amy shared her experience of relationships with self and other in light of having CF.

Interviewer: Do you think that [having CF] changes the way people are with you or the way you feel about yourself?

Amy: I would hope that people wouldn't treat me differently because if you look at it, I'm the same. I'm a girl just like you. We're the same; I just have to do something a little extra, and I have to take maybe more pills than you or things like that. I don't want anyone to treat me differently just because I have CF. I just want them to be normal around me. And all my friends are like that. And most of the time they're like, 'Oh yeah, you have to go, you have your CF,' and then lots of my friends when I'm eating or anything they're like 'Did you take your pills?' Or if I'm, ah, at 1:45 in the afternoon I have to go downstairs to do my mask and if I forget, and I'm just not looking at the time or if I'm doing something else, my friends will be like 'Amy you have to go,' and I'll be like 'Oh thanks.' So I'll just pack up my stuff and go. Everyone's right there for me like that.

Amy viewed herself as being no different from any other girl her age and she did not want to be treated differently because of her disease. In Amy's mind, the only difference between her and others was that she had to do additional things to keep herself healthy. In the early stages of the disease, cystic fibrosis may not be outwardly visible to others. It lays hidden and manifests itself within the body, often without obvious changes to one's outward appearance. What makes cystic fibrosis visible at this stage are the episodic symptoms and regular treatments that call one away from social activities, revealing the invisible and rendering the private sphere public. Once these differences become public, there is a risk of calling attention to one's otherness. These regular separations threaten children's identities by removing them from activities that maintain their "non-different" status and by signifying their absence, reminding others of their difference (Christian & D'Aura, 1997; Williams et al., 2007). In addition to missing social and recreational activities, Amy also missed class time during school in order to attend to her health.

Amy: Well sometimes we'll be doing something fun in class or having a year-end party and I have to leave and go downstairs and do my mask. So if we're doing class work, I'll leave. We have hour classes and I only get a half hour in the morning and a half hour in the end so I have to leave and I miss that work. And that's when I fall behind because I forget about it or it'll be done but I'll just forget to pass it in. So then, that's where I start to fall behind.

Amy contended with the added responsibility of having to do her treatments while in school. This separated her from her classmates and resulted in her falling behind in her learning. This falling behind, or being left behind became an ongoing battle that perhaps added to her feelings of otherness. Some of Amy's teachers were very supportive

and allowed her to stay after school and get the help she needed to catch up. She was appreciative of the extra help she received and realized that her teachers would not normally have done this for other students. She knew that her circumstances were special and that her teachers understood her need to leave the classroom. However, when students receive special help and treatment it sometimes leads to resentment and alienation by peers.

When asked about worries or concerns and to whom Amy would turn for help, she revealed that she had been bullied a lot in the last couple of years. She spoke of a number of friends and trusted adults to whom she could go for support, but despite this, Amy's bullying problem persisted. By leaving the classroom at different times throughout the day in order to receive her treatments in the learning center she drew attention to herself, giving others reason to question where she went and why. She also spent additional time in the learning center because she had been having difficulties academically, due in part to interruptions during class time to complete her treatments. Some of her peers, emphasizing Amy's otherness, may also have viewed going to the learning center for extra help negatively. Amy described her experience of being the victim of ongoing bullying.

Amy: In grade six, there was a girl, well there were actually three girls, and they weren't very nice to me. They didn't like me and they would just do rude things to me . . . They got talked to about it and then it kind of cooled down. Then in grade seven, it happened again and they were just being rude, saying rude things, making up lies and rumors and just things to make people not like me. And then this year it started again. I just ignore it now but you can't ignore it after so long.

Amy's helplessness is visible in this situation. The mean-spiritedness in these acts of bullying hurt and excluded Amy, and no matter what she did, the bullying continued. Fighting back, as she did against her disease did not work in this situation. Standing up for herself or telling the teachers what was happening only resulted in more chiding and led others to label her as a tattletale. On the other hand, turning the other cheek and allowing the behavior to persist gave these girls the power to continue hurting and excluding her.

For all human beings there is a fundamental need to belong and to be seen as one who is valued and worthy of love and affirmation. For Amy, it was difficult to make

sense of the suffering she endured at the hands of her tormentors. One of the ways Amy dealt with the pain was to talk about the bullying to the trusted adults in the learning center where she went to get her masks and help with her schoolwork.

Amy: I'll be in class and I'll be just like, 'I can't take it,' and I'll want to go down to the learning center just to get away [from the bullying]. She's [the trusted adult] usually there the whole day and so I'll go down and do my work in there where I can talk to her and she can help me do my work. Some of my good friends are down there too; lots of my friends stand up for me too.

Bullying seemed to occupy much of Amy's headspace while in school. Inside and outside the classroom, her tormentors confronted her. In the classroom, Amy had difficulty concentrating because she was alert to the whispering, the passed notes, and the giggling that were directed toward her. When she realized that because of her inattention she had missed an important part of her learning, she struggled in vain to catch up by asking friends and fellow classmates for help. When she did not get the help she needed from these friends and classmates, she became frustrated and angry.

Once again, she was rejected, and once again, she was seen as the one who, unlike the rest of the class, did not get it. However, what some of her friends and the rest of the class may not have understood was what was going on in Amy's mind. She was inwardly struggling with hurt, anger, and frustration and her powerlessness to stop her tormentors. She was unable to ignore them and her only escape was to run, seeking the comfort and safety of the learning center where she could vent her feelings and receive validation. It was within this space that she sought refuge, where supportive adults validated her feelings and reaffirmed her worth. Refuge is a "place to flee back to" (Harper, 2001-2013). It is the place where others saw Amy's pain and suffering and were there for her, willing to intervene. It was a space in which Amy felt supported, safe, and cared for. Like Bob, perhaps Amy was seeking a "hospitable space" (Kimes Myers, 1997), a place where she was protected, strengthened, and renewed. In this experience, something showed up in the in-between, within the relationships that Amy gravitated toward in her search for a place to feel at home.

Amy: Part of me kind of ignores it at first, but then you go back and remember it and you think about it . . . Then maybe something will happen that'll remind you of it and then you're like . . . 'Maybe what they're saying about me is true.' You start to believe it and then it's hard

not to believe it and get your mind out of it. Then I'll look and I'll be like 'No, I do have friends that care about me.' They might have gotten mad at me once and said something but I know in the end they would be there for me. And I do have teachers that agree with me, and I've got all these people that agree with me. So I kind of just look at it like, 'Obviously they don't know what they're talking about' because all these people do care about me and are there for me.

Amy tried in vain to ignore her tormentors, but as the taunting and exclusion continued, there was a chipping away at her sense of self. While she said that she tried to ignore them, she felt that she could only do that for so long. While Amy tried not to pay attention to the hurtful comments and actions of her tormentors, she was unable to stop herself from ruminating on them. As she reflected on their words and deeds, she attempted to make sense of what this meant in relation to who she was. Although this sense of loss of belonging and threat to self-concept was indirectly related to her illness, it held meaning with relation to her spiritual health and overall well-being.

Situations that challenge our view of self and sense of place in the world prompt us to look inward and contemplate the meaning of events with relation to beliefs and values that constitute the core of the self. The formation of a spiritual identity, which is anchored by personal beliefs and values, occurs when we see ourselves as a meaningful and enduring part of a larger system of others and world despite experiences of loss, challenge, and suffering (Faull & Hills, 2006). Faull and Hills go on to say that reliance on a spiritual identity enables us to endure and transcend life's losses and challenges more consistently leading to resilience that is more stable and enduring than that which is based solely on external supports and resources.

In her reflections, and by drawing strength from supportive relationships with others, Amy was able to re-frame the image of herself as presented by her tormentors to reflect a more balanced and complimentary view. She countered her tormenter's comments with knowledge that there were people who cared about her and who would be there for her. She was not alone and friendless, despite what they might say. Amy drew on her knowledge that she was understood, valued, accepted, and loved. This unconditional caring, understanding, and acceptance by others served as a touchstone that kept her grounded and enabled her to see herself as a person of worth despite the words of her tormentors.



When asked how she imagined her future, Amy talked about being a dentist or owning her own spa. She realized that becoming a dentist would require many years of school and settled on the notion that she would maybe like to go to community college instead. Perhaps she was contemplating the limited time she might have in her adult life. Instead of spending extra time in school, Amy considered plans that still fit with her goals for success and chose a career that she would enjoy and that she could embark on earlier in her adult life.

Amy: Well I'd hope to grow up and prove to everyone that I can be somebody because people say success is the best revenge. . . . And I would just hope that in the future, the people that pick on me now, and that continue to pick on me, that they soon realize that there's no point because they're only just hurting me, and eventually they'll hurt themselves. So, [I] just [hope] that they'd stop, and just try to be nice to everyone, because when you're mad all the time, there's nothing fun and you're just always grumpy and moody. But if you're happy and you can laugh and joke and play around, you can have a fun life.

Amy believed that the best revenge on her tormentors was not to retaliate with mean words or deeds, but to show them that she can be somebody. She believed in herself and her ability to be successful in life and she had a longing to prove this. This desire to prove her worth to others became another challenge Amy faced in addition to those posed by her illness. Channeling this will and energy into activities that benefited her and that increased her chances of success also served to counteract the depreciating comments made about her by others. In the meantime, she hoped that the bullying would stop. She wanted her tormentors to see that hurting her was pointless and hoped they would come to realize that they were robbing her of a fun life and that they too will be hurt by their actions eventually. Perhaps this last statement is a sign of Amy's belief in reciprocal fairness and immanent justice. A sense that there is a cosmic order to things and that people are punished for wrongdoing seems to be a spiritual understanding that helps Amy find some meaning in her suffering.

### **Lucy (13 Years)**

Lucy handled her illness in a very different way. She did not need to have aerosols or physiotherapy while at school, and the only treatments scheduled during school time were the pills she had to take with her meals. For Lucy, this made it easier to maintain her non-different status in public.

Interviewer: What is it like going to school?

Lucy: It's fun. And then I have a snack break and a lunch and I have to take my pills then too. But it's good because my mom lets me carry them in my book bag. Most kids have to take their pills and take them to the learning center and the learning center teachers have to lock them up. But I don't think that anyone really knows or remembers that I have to take them, so I just take them and get it over with, so they wouldn't realize.

Interviewer: So do your friends know you have CF?

Lucy: Yeah

Interviewer: Do you find that they treat you any differently?

Lucy: No

Lucy told me that her close friends were aware that she has cystic fibrosis and that they treated her "just like a normal person." Lucy also said that she did not talk about her illness with her friends because she found it boring, piercing through the normalcy she fought to maintain. She also avoided drawing attention to her illness by assuming responsibility for taking her own medications at school. She preferred to take her medications herself rather than having to go to the learning resource center because doing so would reveal a sense of otherness that would lay bare what Lucy preferred to keep private. Although Lucy said she would not care if others saw her taking her pills, she continued to do it discretely, avoiding the risk of being viewed as different from others. Evidence suggests that the impact of having cystic fibrosis on children's sense of identity is related to the degree to which they are willing to disclose their illness to others. Some children and families choose to hide the signs of illness or reduce its visibility to lessen the feelings of being different from peers (Christian & D'Aura, 1997; Williams et al., 2007).

Most people with chronic illness . . . use silence as a strategy to manage difficult people or situations. However, they may also partition their experience without realizing it. In certain relationships and settings, expectations of continuity of self and self-presentation outweigh illness and suffering; hence, partitioning experience becomes a habit. They allow themselves to be sick and acknowledge suffering only in private places and close relationships. Otherwise, they try to remain silent about illness and suffering. (Charmaz, 2002, p. 308)

For children with cystic fibrosis, there may be no obvious signs of the illness in the early stages of the disease making it easier to hide signs of illness. Modifying

treatment schedules or treatment spaces to reduce the visibility of the illness are ways that children with cystic fibrosis can retain the appearance of normalcy. For children with cancer, however, the act of hiding illness is much more difficult. The physical manifestations of cancer and its treatment not only necessitate prolonged absences from peers but also result in sudden changes to one's outward appearance that make hiding the illness more difficult.

**Bob (9 Years)**

Like many other children with cancer, Bob was isolated from his peer group during the initial diagnosis and treatment phase of his illness until he was feeling well enough to return to school. Having cancer, he was unable to hide the visible manifestations of his illness, and he talked about his experiences of returning to school after starting treatment.

Bob: After I was diagnosed, I had to stay in the hospital for a week. When I came home, I could not walk on my right foot so I laid on my couch most of the time. When I went back to school, people were a bit scared. They thought they might catch it from me. This year I did a talk at my school. They had some good questions for us.

Interviewer: Wow . . . so people were a bit scared when you went back to school . . . So they weren't quite sure. They didn't understand it.

Bob: They thought they might catch it from me or something.

Interviewer: And what was that like for you?

Bob: Lonely.

Interviewer: Lonely, yeah, yeah. So tell me what happened.

Bob: I started telling people that they couldn't catch it from me and it just develops in them.

Bob felt very alone upon returning to school after his diagnosis. With his bald head and moon face, he looked very different from the other children and they feared that they would catch what he had. Although he explained that they could not catch it from him, they were still "a bit scared." None of the other children would invite him to play with them, leaving him to seek their company. He remembered only one boy who, even though he was a bit nervous, would still play with him and not leave him alone while the others would shy away. This was a very lonely time for Bob where he was deprived of the support and connection to peers that he needed to help him feel a sense of normalcy during a time that was far from that usually experienced by other children his age.

The most distressing emotional symptom experienced by young school-aged children with cancer in one study was a feeling of being alienated (Hedstrom et al., 2003). When Bob was asked what would have helped him during this time, he believed that having a supporter would have made things easier.

Interviewer: So what do you think would have helped at that time in terms of going back to school? Is there something that somebody could have done to make things easier for you?

Bob: Well my middle school . . . if someone had problems or something they would have a supporter go around with them and um, they had supporters at the old school, which is now a day care. Yeah it might have helped a lot of people.

Interviewer: Would that have been helpful for you?

Bob: [Nods affirmative]

Interviewer: How would they help you . . . the supporters?

Bob: Well, they would help you feel better and they would help you if friends were picking on you or something.

Bob felt that having an adult around who was there just for him would have helped him to feel more protected and accepted by his peers. Although the presence of an adult might have had the opposite affect by making him stand out more starkly in his difference, perhaps he felt that close proximity and acceptance by an adult would mitigate other's fears of contagion. Nevertheless, he felt the need for someone to be present with him, to make him feel better about himself and what was happening and to act as a facilitator to help foster connections with the other children.

Without this person, Bob was left to initiate peer connections on his own, often feeling their reluctance to be near him. He felt shunned and alone, dealing with an illness that made him alien, causing the other children to fear becoming like him. His illness made him a pariah, leaving him without the comfort and normalcy of play within a trusted and accepting peer group. Bob also relayed recent experiences of being bullied. Although later when Bob was not present, his mother revealed that he had an exaggerated sense of others' intent to harm him. Given his previous experiences of exclusion and of physical restraint and infliction of pain for medical reasons, perhaps Bob understood his right to be free from the infliction of physical and emotional torment by others.

This experience of being rejected by others because of his illness has had a lasting effect on Bob's sense of self. When asked to describe himself, Bob's first

response was “I’m done treatment.” The fact that this was Bob’s initial defining feature of self speaks to the impact of the disease on his sense of identity. Being done treatment was an important milestone in Bob’s life. It was a reference point that signified a new chapter in which he was no longer different from others. When asked what his friendships were like now, Bob said that he was no longer concerned because he has been finished treatment for a year.

Although he still needed medical follow-up, and still bore the hidden scars of his illness, cancer was no longer a part of him. He felt that he was now able to blend in with others and was no longer seen as different now that his illness was no longer visible. However, adolescent cancer survivors often become caught in a paradox between a cancer identity and a survivor identity. Lingering physical, emotional, and cognitive late effects accompanied by an existential uncertainty can leave survivors struggling to fit in with non-survivor peers, reminding them of their difference and intensifying feelings isolation (Cantrell & Conte, 2009; Jones et al., 2011). Inability to accept the illness identity and integrate it into a renewed sense of self as survivor may also result in a fracturing of self in which the rejection of the illness identity leads to poor adherence to health promoting behaviors (Tilden, Charman, Sharples, & Fosbury, 2005).

Paradoxically, although the cancer experience can leave survivors feeling uncertain about the future and struggling to fit in, there is also the potential for immense psychospiritual growth and identity formation. Through finding meaning in the experience and integrating uncertainty, survivors can develop a deeper appreciation for life, a greater awareness of life’s purpose, and feelings of hope for the future. More than simple coping, this process of meaning making can lead to profound changes in identity and worldview that contribute to longer-term thriving and resilience (Cantrell & Conte, 2009; Parry, 2003; Parry & Chesler, 2005). Poignant examples of this phenomenon can be found in the stories shared by other children with cancer who have found meaning and purpose in joining others in the fight (Coast to Coast Against Cancer Foundation, 2012, <http://www.coasttocoastagainstcancer.org/ambassadors/>)

In keeping with Woodgate’s (2006b) findings, life is never the same after having childhood cancer. Even after completion of treatment, the families in Woodgate’s study expressed uncertainty about the future and worries about reoccurrence and fear of

potential death. In her family narratives there seemed to be an ongoing struggle to survive. In a previous article written by Woodgate and Degner (2003), using the same data, the pervading phenomenon revealed was that of “keeping the spirit alive.” For these families, keeping the spirit alive was necessary not only for surviving the cancer experience, but also for longer-term thriving. They vowed not to let the cancer destroy their spirits and adopted a fighting stance, much like the one Amy described previously.

For Bob, perhaps finding a place for himself in the world as a survivor with an identity that integrates the cancer experience as one of learning and triumph may help him to adopt an identity that engenders a sense of thriving that will sustain him as he meets future challenges. As Bob enters adolescence, there is the potential for him to reflect on his experience more abstractly, enabling him to further contemplate the effects of his cancer experience on his sense of who he is.

### **Jake (11 Years)**

Unfortunately for Jake, at the time of our meeting the manifestations of illness were still very visible and debilitating. As my conversations with Jake began, we talked about his interests that centered on Pokémons and video games. When I asked about friends, Jake revealed that he had one best friend who he also described as his archrival, a portrayal that stemmed from their competitive collecting of coveted Pokémon cards. Jake also described him as one of the few friends who still visited him. When asked about other friends, Jake revealed that a number of them did not come over anymore. He knew of the reasons for some friends not coming to visit but was unsure of why the others stopped coming. He did say however, that he did not think that his illness had any impact on the loss of these connections.

Although Jake did not believe that his illness had anything to do with his diminishing peer connections, there are aspects of his illness that necessitated separation and that prevented him from engaging in activities common to other children his age. Serious illness often disrupts lives and relationships due to forced exclusion from social activities (Fagerskiold & Mattsson, 2010; Griffiths, Schweitzer, & Yates, 2011; Jones et al., 2011; Wright, 2008) and is a source of difference that sometimes leads to isolation from peer groups (Burns, Sadof, & Kamat, 2006; Christian & D’Aura, 1997; Fagerskiold

& Mattsson, 2010). At a time when social supports are needed most, illness may become a barrier to social connections, threatening one's sense of self as a valued other.

Jake had missed a lot of school in the past year because of his cancer, and as a result, he had lost the taken for granted social connections that were once part of his everyday interactions. This included contact with others his age as well as teachers who might have provided a supportive presence in his life. These separations led to a dwindling social network in which Jake was left with very few friends his own age. In addition to missing school, the ravages of cancer stole his mobility, preventing him from engaging in the activities others his age enjoyed without effort.

Within months after this interview, Jake learned that his cancer was no longer treatable and was left to face the end of his life. As he progressed through his illness, he was left with fewer and fewer people he could rely on for support. When I inquired about the important people in his life, he requested that we move on to the next question, indicating either an inability to articulate his thoughts or an unwillingness to answer. I then probed deeper by specifically asking about his parents, eliciting an answer that was surprising, revealing underlying feelings that seemed to reflect his overall state of being.

Interviewer: So who are the important people in your life Jake?

Jake: Um . . . Can I go on to the next question?

Interviewer: Sure. What about your mom and your dad?

Jake: Uh, one of them. The other one's just a driver . . . Um, one's the driver; the other one's the important one.

Interviewer: Mmm hmm . . . Who's the driver?

Jake: The dad. He's just a driver, a servant, and an annoyance.

Interviewer: Oh? And what makes you feel that way?

Jake: Because he's annoying.

Interviewer: Mmm hmm, in what way?

Jake: A lot of ways [bearing down on the paintbrush as he paints on the canvas]

Interviewer: Mmm hmm . . . It sounds like you're mad at your dad for something.

Jake: Mmm, not really. He's just very annoying and he makes me mad all the time.

Interviewer: What makes you mad?

Jake: A lot of things that he does.

Interviewer: Like what?

Jake: Lots of things . . . [Quietly] I wish I had some . . . [Voice trails off]

Interviewer: So anything you can name?

Jake: If I had to name all the things, you'd be listening till tomorrow.

Interviewer: Okay, give me an example.

Jake: Umm, he snores loud.

Jake articulated his anger and frustration, not only in his tone and in his words, but also in his actions as he vigorously bore down on the canvas with his paintbrush. He described his mother as the important one in his life while his father was relegated to the status of servant and chauffeur. In a later telephone conversation with Jake's mother, she relayed that Jake had acknowledged to her that he could see how tired she was becoming in her care for him. This leads me to wonder if perhaps Jake felt resentment toward his father for his lack of involvement in his care. Jake's mother stayed with him in the hospital and was the one who was consistently there for him to ensure his comfort. She was Jake's primary care giver and was the one who arranged appointments and attended to all of Jake's healthcare needs while his father perhaps did what he could to support the family.

The lack of social connectedness in Jake's life, along with his reported resentment toward his father reflects a sense of aloneness. The horror, pain, uncertainty, and lack of information about the outcome of his illness at the time of the interview, accompanied by his apparent isolation, gave me the impression that he was suffering alone. Except for his mother, who was "the important one," he seemed to have very few opportunities for meaningful engagement with caring others.

Given the human need to have a place in the world and a sense of belonging to something outside of the self, I wonder how this affected Jake's sense of identity. "Identity formation is a complex and constantly evolving process, and individuals are constantly discovering who they are in relation to others" (Tilden et al., 2005, p. 321). For children with cancer, isolation from peers is one of the most difficult aspects of treatment that not only affects their sense of connection but also their sense of identity (Griffiths et al., 2011). With illness so pervasive in his life, I wonder how Jake processed this in relation to his sense of self. With very few people to talk to, perhaps he was inwardly struggling to find meaning in such a horrendous experience and an uncertain future. Jake's expressions of anguish led me to read his suffering as deeply spiritual. Angry, isolated, and in pain, he lived with uncertainty waiting for the other shoe to drop. This omen of the future was imbued with threat, leaving him to contemplate the future and his place within it.



### **Quadeher (13 Years)**

Like Amy and Lucy, Quadeher also lamented the difficulty of being separated from his friends because of his illness. During the initial stages of his illness and treatment, Quadeher was required to live away from home for eight months in order to be close to the hospital. This was a very difficult time for Quadeher because he was deprived of the peer supports that were so important to his well-being. He even considered some friends to be his brothers and sisters. In essence, separation from these friends deprived him of the closeness of family that was an important part of his thriving in the face of illness.

Quadeher felt a deep sense of disconnection from others because of his illness. When asked what it was like to have cancer at his age, he said it was “strange.” Feeling strange denotes a sense of being “from elsewhere, foreign, unknown, [and] unfamiliar” (Harper, 2001-2013). Uprooted from a place of belonging, Quadeher was thrust into the world of medicine, where unfamiliar faces and places formed the backdrop for living the fear and uncertainty of his illness. No longer at home, he was surrounded by the unfamiliar. In a life altered by illness, Quadeher felt like a stranger in a strange land. Perhaps not even at home in his own body, he became alienated from self and others.

Although Quadeher could not articulate specifically how he felt different from others, he lamented that things were a bit tougher because he was now struggling with math and had to be moved to another class. Although Quadeher’s cognitive decline was not visible in a physical sense, it manifested itself as a difference in ability that set him apart from others. In addition to affecting one’s physical appearance, cancer treatment can also affect cognitive functioning (Jones et al., 2011). Being moved to another class made these cognitive struggles visible to others much like a physical difference would. This separation from his friends made him feel different adding to his feelings of alienation.

### **Matt (13 Years)**

Like Quadeher, Matt also struggled with his schoolwork. Illness caused him to miss about three quarters of his last school year. This, along with the possible cognitive effects of his treatments, resulted in him falling behind his peers, perhaps leading to a sense of inferiority. As he described his challenges with his schoolwork, it was readily

apparent that this was very concerning to him. Although he felt that he was getting the help that he needed, he was still concerned with the effects illness was having on his academic achievement. Feeling competent, and experiencing a sense of accomplishment academically adds to children's sense of self as capable (Ball et al., 2010). For some it may even be a measure of self-worth and an indicator of future success in relation to life goals and aspirations. As he contemplated these losses of self and place, perhaps there was a wondering of what this would mean for him now and in the future.

### **Summary**

As these children battled their illnesses, they were confronted with changes to self and identity along with added responsibilities and limitations that set them apart from others. Within the children's stories were also indications of disconnection with regard to body, time, space, and relations with others. Being viewed as "other" by their peers or feeling separate due to illness-imposed segregation, isolation, or silence, children sometimes became alienated from themselves and the communities of support that were so essential to their spiritual well-being. Those who were cut off from dialogue about illness and existential matters may not have had the chance to explore meaning and purpose in illness and in life, and perhaps they were missing an opportunity for meaning making that may sustain them as they meet future life crises.

The spiritual is implicated here in the children's expressions, beliefs, relations, and meaning making. In the following chapters, I continue with an exploration of the spiritual within children's relationships with self and others, including the transcendent. I looked for the spiritual in the in-between, in the negotiation of relation with self and the surrounding world and in the meanings children gave to these experiences.

## **Chapter 6: Transcendent Relationships**

Language for the spiritual or a transcendent other that resonates with children who range in age from nine to fourteen years can be challenging, and it seemed to help to begin with familiar terms such as religion and church. While this served to direct the children toward this line of questioning, it also opened the door to an inquiry about the presence of other spiritual connections and of formal and informal spiritual teaching in their lives. Regardless of the degree of affiliation with religion or church communities, all of the children reported that they knew of god and had formed opinions about god's existence and role within their lives. Once this connection was made, I was able to inquire into the children's beliefs about god and what, if any meaning this connection had in their lives. For some, god played an integral part in the forming of ideas about self, life, living, illness, and existence beyond the physical. For others, there was uncertainty about god's existence, a superficial knowing, and even doubt and indifference toward god as a transcendent other of meaning in their lives.

### **Spiritual Beliefs and Meaning and Purpose in Illness**

#### **Amy (13 Years)**

Amy had a strong connection with god and her church community and saw god as a constant presence in her life. She found great strength in her religious faith and drew on this as she navigated her illness and sought answers to questions about illness, existence, and ways of living her life. Beginning with reference to her uncle's illness, she goes on to relate her understanding of god's purpose for illness in the case of her uncle and in that of her own.

Amy: I think that Uncle John got sick because he needed to be woken up and realize what he was doing . . . So I think god helps you in that way. So sometimes, when you do get sick, you do wake up and realize it. And other times you've forgotten to do something, like you forgot to do your mask and you wind up in the hospital, or you didn't take your pills and now you have something really wrong in your system and you wind up in the hospital. But you remember it for next time. You remember that pain and you don't want that again.

Amy viewed illness as a wake-up call from god, a call to remembering what we should be doing to keep ourselves healthy. Perhaps when the body is silent, it is easy to ignore or forget its needs. It is only when it begins to break down that we experience a

sense of vulnerability. Amy's rebellious body, unrelenting in its need for attention, became adversarial in response to forgetfulness or neglect. In her constant struggle to find balance between freedom and responsibility, her choices dictated the response of her body.

Pain and suffering was the voice of the body, reminding Amy of its limitations and finiteness. While some might become disheartened or hopeless when faced with repeated signs of progressing illness, Amy was able to transcend these experiences with a sense of purpose and optimism. With god as her teacher and guide, she was able to find meaning in suffering as an opportunity for learning and growth. In times of bodily silence, god was also there to remind her of her responsibilities. In times of resistance and struggle for freedom, god called her back to the path toward wellness, motivating her to adhere to a daily treatment regimen that at times was restricting and burdensome.

Canda's (2001) interviews with adults who had CF are reminiscent of Amy's feelings of being called back by god to the path toward wholeness and health. For many of Canda's participants, as their physical condition deteriorated, their focus on the spiritual intensified. Exacerbations of illness prompted them to reflect on their own mortality and provided grounds for them to not only step up efforts to stave off progressing illness, but also to focus on their appreciation of life and commitment to high quality social relationships and their connection to the spiritual. It was the existential threat of illness that helped them to refocus on what was important in life and prompted them to draw on the spiritual as a sustaining strength that grounded them in living, helping them to live life more fully.

In Amy's understanding of god's purpose for illness, there was also an element of responsibility and blame. There was a sense that illness is caused by things we do or fail to do to keep ourselves well. This thinking seemed to reinforce her personal responsibility for maintaining her health.

Amy: Well . . . if someone would have gotten hurt, I would've been like 'Why did god have to do that?' Then I stop and I think no, it wasn't his fault because god doesn't control us. We make our own decisions and we make our own choices. So when you get sick, it's no one's fault but your own because whatever you did to make yourself sick, you shouldn't have done [it] . . . I don't think people get sick because they've done something bad . . . I don't necessarily think like that. I do think that if someone does

something wrong, they will get punished for it, or at least they should. And maybe later on in life they do get punished for it and then they remember and so it's their choice on what to do. If you do bad things, you're going to get punished for it, and if you make wrong choices, you're usually going to suffer for them or have to fix them.

In this view of illness, Amy relieves god of having a hand in its cause and assumed a protective stance. While she initially blamed god at times for the suffering of others, she later recanted this belief and adopted alternate explanations that shifted the blame from god to the one who was ill or to the one who deserved punishment for wrongdoing. Amy formulated an explanation that made sense to her, that enabled her to retain an image of god as good, while also maintaining a sense of individual control, a sense of self, and the free will to choose. This way of viewing illness fits with Fowler's understanding of reciprocal fairness and immanent justice as being common among children of this age (Fowler, 1981; Fowler & Dell, 2004). Within this narrative, however, Amy was able to reflect on these meanings and find purpose with regard to how she lived her life. By viewing illness and suffering as a by-product of her own actions, she accepted responsibility and maintained some control. Instead of feeling abandoned, she continued to sense god's presence, supporting her by reminding her of the meaning and purpose in suffering.

Amy's beliefs about self-responsibility with regard to her health speak to how spirituality and health behaviors can be intertwined. Even among healthy children with religiously diverse backgrounds, spiritual views seem to have a positive influence on health promoting behaviors (Gersch et al., 2008). Finding meaning and purpose in suffering also serves as a protective factor, contributing to resilience. It enables adolescents to make sense of the unpredictability and unfairness of life and to move beyond it with a sense of coherence, optimism, and hope (Raftopoulos & Bates, 2011). This may be significant to healthcare providers especially with regard to promoting health sustaining practices among youth and points to the significance of listening to young people's metaphysical and spiritual views and questions.

### **God as Helper and Healer**

#### **Amy (13 Years)**

When asked about god's role in illness, Amy described her beliefs and understandings.

Amy: I think that [god] would help you through it at your worst times. If you were ready to give up because you thought you had enough of it, I think you could turn to him and say . . . please help me. I can't, I don't think I can do it on my own anymore and he would help you through it . . . He could help [by giving you] the feeling that there's someone there with you and that he's ready to face it with you . . . He just helps if you need him. If you just need to talk to him for a little while, he'll listen. He helps in all different ways because everyone needs help in different ways . . . I also think that if you want him to [guide] . . . you, just to show you how to do it, he would also help you with that.

Getting to know Amy, it became apparent that god has been a meaningful and enduring presence in her life and has provided her with companionship, support, and guidance in challenging times. Her belief in god and trust in god's presence was comforting and provided a source of strength, letting her know that she was never alone in her suffering. Belief in a transcendent other as an available source of unconditional love, protection, comfort, and guidance can be a foundation for coping during low-points in adolescents' lives and has also been identified as a spiritually-based protective factor contributing to resilience (Raftopoulos & Bates, 2011).

As Amy's story unfolded, it became apparent that her spiritual beliefs were very important in processing events and in making meaning with relation to living and having cystic fibrosis. Amy shared the experience of having god in her life and of how god's presence held meaning for her as she struggled with her health.

Amy: Well I've been, I don't think I've been at my worst but I've been pretty bad, and I felt like I was ready to give up. I know he [god] helped me through it because he just, I felt like someone was just there telling me to keep going. This is the way to go. Forget about what people say. Forget about those. Take this way. Do it this way. And I just kind of listen to whatever I felt . . . and it helped me get out of that garbagy feeling. And just when I was ready to give up, I was ready to keep going so . . .

Interviewer: So it gives you strength to . . .

Amy: Yeah, and it gives you power, and I think in the end you learn from it all and it's going to be a great lesson that you learn . . . probably one of the most important one you will learn.

As Amy reflected on experiences in life when she was ready to give up, she recalled feeling the presence of god, guiding her and encouraging her to keep going. Feeling defeated, Amy called on the strength that came from god's voice, feeling a power that flowed through her, enabling her to act against the constraints of her illness. Encouraging and inspiring words were channeled as positive energy that Amy harnessed

and internalized, giving her added strength to persevere when the burdens of illness threatened to overcome her. By channeling this spiritual energy, Amy was able to bolster her belief in herself as capable of transcending the difficulties she faced, leading to a renewed sense of hope and optimism.

Amy also realized the learning that took place in the midst of suffering. By finding the strength within her that was mediated by her belief in god and god's guiding and encouraging words, Amy felt more powerful. She was able to shed the negative self-talk in favor of a stronger, more powerful voice that guided her toward victory. As this power became her own, she learned how to see her situation in a different way, to view herself as capable of overcoming, in this situation and in others to come. The narrative of suffering as a learning experience was transformative for Amy. It prompted her to reflect on life and living, resulting in a story of triumph in the face of defeat.

Amy's belief in the enduring presence of god in her life provided a reliable source of strength and unconditional support.

Amy: He'll always be there when you've done the worst thing you can imagine. He's going to be there, and if you really are sorry for what you did, he will believe you and he will forgive you. You may not know, but I'm sure, when you do pass away and you're ready to enter into heaven, [with a laugh] . . . or wherever you go, I'm not sure . . . he's going to be there. He's going to tell you that he does forgive you and he loves you no matter what. He always will . . . That's the one person, when I feel like no one cares about me, if I'm having the worst day ever, I'm like no one cares about me, no one loves me, I stop and I think god does and he always will . . . So you can always have one person there for you. So, when people say they have no one, I tell them that they always will have one person . . . and that person is the most important one you'll have.

As Amy recounted her daily experiences with illness and challenge, it is not difficult to see the positive outlook she had on life and the maturity with which she handled the challenges that confronted her. A key feature of her coping and of her meaning making in difficult life events seemed to stem from a profound sense of god being an important and enduring presence in her life. This sensing of god's presence and the personal relationship Amy had with god served not only as a means of coping, but was also very life affirming. Amy believed in a forgiving god, one who loved her unconditionally despite her wrongdoings.

### Lucy (13 Years)

Unlike Amy, Lucy did not have strong connections to a church community. Although Lucy had not heard of the word spirituality or religion, she was familiar with the word church. She said that she had never really thought about church or god that much and that she did not pray or talk to god. However, when questioned about what she knew about god, she had pre-formed thoughts that pointed to the fact that she had already reflected on god and the meaning of this relationship in her life.

Interviewer: What do you understand about god?

Lucy: That he's there to help us.

Interviewer: How does god help us?

Lucy: He helps guide and make our decisions and he doesn't always . . .

Well it's not him that makes the bad decisions, it's like our emotions and stuff that gets us in a position where we just want to . . . like yeah.

Interviewer: So how else has he helped you?

Lucy: Ah, like pass my swimming lessons and ah, like make me have confidence in myself and believing that I can do things that I don't think I can do; and then I end up doing it and stuff.

Interviewer: Mmm hmm. Good. [Value laden word—could be leading] What else?

Lucy: I know that I can absolutely get through a physio and aerosol without putting up a big kerfuffle.

Interviewer: [Chuckle]

Lucy: [Chuckle] ah, and then just getting it done and getting it over with so I can go and like have fun again.

Although Lucy said that she had not given god much thought, she believed that god was there to help her. She did not pray or talk to god very much but believed that “god helps guide and make our decisions.” Like Amy, Lucy saw god as a guiding voice that helped her make good decisions and kept her from making bad ones. She did not blame god for her bad decisions but attributed these decisions to her emotions and her own free will to choose.

As she contemplated choices in her life, she struggled with what she ought to do as opposed to what she wanted to do. God's intervening voice was a mediating presence that served to, as she put it, “stop her in her tracks” and “make her think again” so that she did not follow blindly without considering the consequences. This presence of voice served her well as she struggled with the constraints of her illness and with her resulting emotions. Reflecting on god's voice was a means of living with awareness, of looking to those signals and signs that urge us to stop and evaluate our thinking and behavior. In



doing so, Lucy was able to weigh the good and the bad and make choices based on her understandings and messages received about right ways of living and being.

With regard to why people become ill, Lucy shared her belief that “illness just happens” and that even though “[god] thinks that it’s not right for people to get sick,” she said that she “didn’t think god could do anything [to prevent it].” She saw illness as being a result of “a little bit of everything,” including the choices she made and her responses to the challenges imposed by her illness. According to Lucy, god was there to help her make the right choices, ones that aligned with those that would maintain her health and well-being. Like Amy, Lucy’s beliefs about god seemed to be supportive in sustaining health-promoting behaviors.

When she spoke of god’s voice of reason with relation to staying healthy, she relayed messages that mirrored those from her mother, such as “we should go to bed” and that god helped her believe that she could “absolutely get through a physio and aerosol without putting up a big kerfuffle.” She drew strength from knowing that god was there to help her. God helped her believe in herself and gave her the confidence to do things she did not think she could do, like passing her swimming lessons and coping with the demands of her illness. As Lucy drew on these beliefs, she was fortified in the knowledge of self as capable, helping her to face and overcome the challenges of her illness and other aspects of her daily life.

In interviews with children of Muslim, Jewish, and Christian religions, Robert Coles (1990) recounted conversations in which the children revealed how god provided guidance for understanding and living in the world. Although these messages from god seemed to mirror those from significant others in their lives, the children claimed that the voice they heard was uniquely different. For children in Cole’s study, god’s voice was one of authority, love, and compassion that helped them in times of need. Although children’s views of god might reflect the ideal of what they draw from relational experiences with closely related others, attributes children give to god are uniquely different (Knight, Sousa, Barrett, & Atran, 2002).

While Lucy’s beliefs about god mirrored some of those held by Amy, there seemed to be tenuousness in Lucy’s convictions and in her relationship with god. Her lack of engagement with god through contemplation, prayer, or conversation also

indicated that maybe this relationship was not overly meaningful in her life. However, the silence in this relationship does have relevance. Perhaps it is merely an extension of Lucy's sense of self as capable of solving her own problems, eliminating a need to pray for help. It could also be related to family silence around illness and its meanings that precludes any foray into existential or spiritual wondering. It may also reflect the lack of family involvement in a religious community. Living outside a religious community, some families might struggle to find answers that make sense of the sometimes-unexplainable aspects of life. Without a framework of meaning, perhaps Lucy avoids asking the tough questions knowing that there may be no definitive answers. Life is full of mystery and uncertainty; and adolescents often draw from various frameworks while searching for answers to life's big questions (Hyde, 2008). At the very least, engaging Lucy in discussions about existential meaning and purpose in illness may offer her the opportunity to reflect on these deeper issues of life. These may in turn contribute to future resilience.

### **Quadeher (13 Years)**

Quadeher maintained a strong connection with god and his church community. He attended Sunday school and youth group once a week and attended summer bible camp every year. Although he did not remember specific lessons learned within these groups, he related his enjoyment of hanging out in a comfortable environment playing games and sharing food with friends—a place where he felt at home and perhaps “at one” with himself and others (Pearmain, 2005).

Quadeher described god as “awesome” and believed in god's ability to heal people. He also relied on god's power to help him get better and to help him in times of need. Quadeher maintained his relationship with god through prayer.

Interviewer: Do you ever talk to god, or pray to god?

Quadeher: [Nods affirmative]

Interviewer: So what kinds of things would you talk to god about?

Quadeher: [Took some time to think] . . . Family

Interviewer: Mmm hmm.

Quadeher: Help

Interviewer: Help. Mmm hmm. So what would you ask him for help with?

Quadeher: Like whatever, whatever I might be having trouble with.

Quadeher revealed his trust in god as a source of help for him and his family in times of need. Although Quadeher was not forthcoming with details of his requests for help from god, he later revealed concerns for his family because of his illness. During subsequent conversations, Quadeher mentioned the financial burden that his illness has caused his family and the fears he had about not getting better. Although he felt that things had changed a lot because of his illness, he continued to rely on god for help, perhaps maintaining trust in god as a healer and in god's ability to help him overcome his illness.

Although there was a lack of detailed articulation in Quadeher's description of god and his faith, the tone of his narrative expressed a certainty and conviction of belief. In his prayers, petitions for help indicated a sense of vulnerability and powerlessness in certain life situations. The meaning of god for Quadeher can be found in his description of god as "awesome."

### **Connections to God: Prayer, Ritual, and Responsibility**

#### **Amy (13 Years)**

Early in my conversations with Amy, it became evident that prayer was an important ritual in her life. She said she talked to god and prayed regularly as a means of maintaining this connection.

Amy: I pray for him to keep my family safe and [to] keep my friends safe and let them live long and healthy lives. [I pray for him to] help the doctors and scientists working on cures . . . for people with CF and everybody with cancer. I don't just pray for myself . . . I pray that I grow up and live a long life, and have kids, and have a husband, and . . . just to have a good, fun life. [I also pray for god] to forgive me for my sins if I say mean things to my sister or to my parents or just get in fights and say rude things to my friends . . . And if somebody that I know passed away or is sick or anything, I asked him to help them through it. And there was a lady that had just passed away a couple of weeks ago . . . I asked him to bless her and keep her safe, and I know that she would have gone to heaven because she was such a nice person and she'd never do anything mean.

Amy's prayers for others mirror her aspirations for her own life. She prays for the safety, health, and long life of her family members and friends and for a cure to be found for cancer and cystic fibrosis so that everyone will be cured. In these prayers are signs of what she hopes for herself. She hopes for a cure for her own illness, and she hopes for a

long life, one with children, and a husband . . . “a good, fun life.” In the same breath, she asks for forgiveness for the sins that she has committed, for getting in fights and for saying mean things. Amy’s need for forgiveness relates to her belief in reciprocal fairness and immanent justice. In order to realize her hopes and dreams she must live in accordance with what god expects of her and recognizes the reciprocity and responsibility in this relationship. God is a teacher with expectations guiding Amy in her ways of being with self and others.

What is striking to me in this revelation is Amy’s emphasis on having a long life. Although she did not talk directly about her knowledge that the average life expectancy for people with cystic fibrosis is middle age, she did talk about the concerns she had about not being able to have children or having children with cystic fibrosis. Given the open communication within her family about her illness and her expressed knowledge about its effect on childbearing, it is likely that she had knowledge of its life-limiting nature as well.

In the not so distant past, CF cut life short in early adulthood. However, it is now possible for adolescents and young adults with CF to plan for a future that in previous years would have been untenable. With dreams of an elusive cure and feelings of optimism in light of emerging technologies, many children are now able to look toward the future with hope that may ground them in their living and in their struggle to maintain their health (Jessup & Parkinson, 2010). With this knowledge, Amy lived her life with awareness, self-monitoring her behaviors, and seeking forgiveness for wrongdoings. All the while, she maintained hope for a future in which cystic fibrosis is prevented from stealing her dreams.

### **Tony (10 Years)**

Tony was also affiliated with a local church community and attended weekly services with his family. When asked what god is like, Tony described god as friendly and nice. He said god was invisible and that god helps keep people alive, healthy, and safe. He also believed that god wants us to pray, live a good life, and be nice to one another. Although Tony talked about doing the rosary as part of a former family ritual, he said that it happens infrequently now and that he does not pray much and does not talk to god very often anymore. When asked what he did at church, Tony described the rituals of

sitting, kneeling, standing, and praying. He remembered the singing and the repeating of words, although he did not remember the messages conveyed at these services or the meanings represented. This is consistent with Fowler's (1981) "synthetic-conventional" stage of faith in which meaning cannot be extracted from symbol.

Although he did not recall the messages conveyed in these church services, he was very excited to tell me that he was now able to take the bread and wine. In Tony's church, the taking of the bread and wine is a symbol of communion with god and fellow followers of Christ. The bread symbolizes Christ's body, while the wine symbolizes his blood. The symbolic ritual of accepting the body and blood of Christ is to be reflectively aware of god's presence in one's life and to give thanks for Christ's sacrifices for humankind. Bhagwan (2009) discusses the importance of being sensitive of the need for children to be involved in family or community traditions or rituals because they represent a bond to a spiritual community that contributes to children's identity formation and feelings of connectedness to something greater than themselves.

For Tony, the receiving of the bread and wine was a symbol of the maturation of his membership in his church community and was a rite of passage that enabled him to participate along with adults in a ritual that gave concreteness to his relationship to god and others. Tony also displayed a sense of pride in his recent appointment as an altar server. Although he had not yet received his training, he was very excited to convey his capacity and role as a full-fledged member of his church community. Moving beyond childhood, he was developing an identity that embodied the spiritual and his growing responsibilities to others. These rites and rituals seem to awaken the spiritual in the child and provide tangible symbols of belonging (Blumenkrantz & Hong, 2008).

### **Bob (9 Years)**

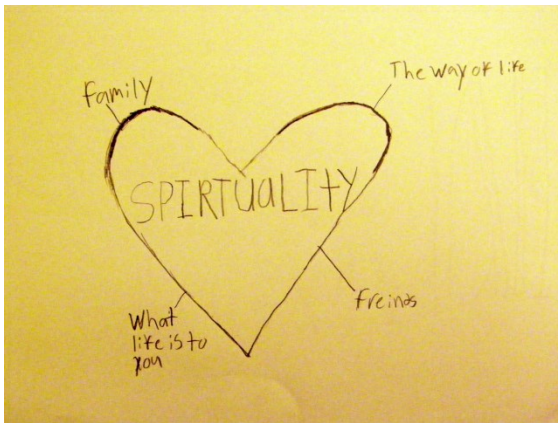
Bob and his family were members of a religious community, and Bob attended weekly Sunday school along with his cousin. He said that he learned about god and Jesus in Sunday school, but like Quadeher and Tony, he was unable to recall the specific lessons that he had learned. Although Bob had not given his relationship with god much thought, he did engage in regular prayer with his family before supper and at bedtime. He said that this was his way of maintaining his relationship with god. Although Bob believed that Jesus and god watch over people when they are sick, he could not recall

thinking about this when he was first diagnosed at the age of five. Further exploration of his experiences will provide some clues to how younger children might access the spiritual as they live the suffering in illness.

### **God as Unreliable**

#### **Matt (13 Years)**

Matt did not have strong connections to a church community and did not consider himself religious. Despite having attended church only a few times with his father, he revealed some well-formed ideas about spirituality and the meaning this held for him personally. Following the first interview, Matt reflected on what we talked about and created a depiction of what spirituality meant to him.



**Figure 6.1: Spirituality**

Matt viewed spirituality as “the way of life,” “what life is to you,” and “how happy you are.” For him, it was “family,” “friends,” and what is in the heart. When asked about his belief in god, Matt expressed his doubts in god’s existence.

Interviewer: Do you think that there’s anything beyond this?

Matt: Nope

Interviewer: No

Interviewer: Any beliefs in a higher power or god?

Matt: Not really

Interviewer: No?

Matt: Kind of

Interviewer: Kind of? What, what do you think is there?

Matt: Heaven, maybe?

Matt revealed his uncertainty about the existence of god and heaven. However, when asked if he had ever felt like there was something or someone around him, guiding him, out there somewhere beyond the physical, he hung his head and began to cry. After

taking some time to compose himself and collect his thoughts, he then shared his experience of losing a friend at the hospital when he was first diagnosed, lamenting that this friend was not even a year-old when he died. “Tears communicate what words cannot say. Tears call out for comfort, solidarity, and relief” (Peltomaki, 2008, p. 227).

Troubled by the thought that someone so young could die, Matt felt pain in the remembering. Even though he harbored some doubts about god and heaven, he talked about sensing the presence of his friend around him. While exploring the experiences of cancer survivors with a focus on identity, meaning making, and health promotion, it was found that:

Experiencing the death of friends prompted participants to face their own survival. A 12-year-old said, ‘One of my old friends died, so it kind of makes me wonder why God took her life and not mine.’ Coping with such life-altering events impelled participants to question their views of others and themselves. (Jones et al., 2011, p. 1035)

Adolescents who have experienced the death of a friend or loved one are often prompted to evaluate their beliefs resulting in challenges to their developing view on the world and living (Balk, Zaengle, & Corr, 2011). Adolescence is also a time when there may be a questioning of spiritual beliefs and traditional norms (Bussing et al., 2010). Perhaps Matt was struggling with the concept of god’s existence when questioning the death of someone so young. How could god have allowed this to happen?

Matt also grappled with this contradiction as he tried to make sense of life and living as well as death and what is beyond it. Matt knew that this baby had cancer like him and perhaps ruminated on the idea that regardless of age, no one is guaranteed a cure. This baby, who was no longer present in body, remained connected to Matt, perhaps reminding him of the fragility of life. This transcendent connection or sensing the existence of a spiritual other is a phenomenon that others have spoken of as well (Ortiz, 2003; Canda, 2001). Canda recalled the connection he felt to his brother who had died of cystic fibrosis.

I felt like he was present in the wind when it blew . . . He liked crows. I’d hear crows or see a crow and I would feel reminded of his presence. It was almost like something of him re-entered the elements of the natural

environment. (I felt that way) especially during the three year period when I did ceremonies for him. That was a particularly vivid sense of connection with him, partly because it was helping him in his after-death process, but it was also a feeling of him helping me, like when he was alive, we were brothers helping each other. So sometimes I have that feeling that he is present and supportive. I don't take these things literally or concretely though. I just accept it . . . as a gift. (p. 127)

This felt connection with his friend who died remained with Matt for well over a year. He still felt the grief of the loss and likely struggled with the spiritual questions of how this could happen to someone so young. Perhaps he was also wondering "Why not me?"

As Matt contemplated the unfairness of the loss, perhaps he was also searching for answers. This sensed presence prompted him to think about what lies beyond the physical. Although he held doubts about god and heaven, the spiritual presence of his friend gave him cause to wonder about the afterlife. Survivors of childhood cancer often struggle with these fundamentally unanswerable questions. While some might accept that illness and death just happen and choose to focus on the personal strength and growth that can be realized in the suffering, others may stop searching for answers due to frustration with the irresolvable nature of the questions. Still others may go on questioning and searching for answers despite these frustrations and contradictions. Those who are able to make sense of their experience are usually those who are most articulate about how they have changed and how they were able to renew a sense of meaning and purpose in their lives (Parry & Chesler, 2005).

Perhaps Matt needed guidance in his search to understand this spiritual conundrum. In his silence, he seemed to be struggling to find plausible answers that might lend some comprehensibility to a world where loss and suffering overturned any previously held notions of safety and of life as continuous. I also wonder if perhaps his suffering went unrecognized by the adults around him. In his silence, his grief and spiritual questioning may be driven underground. Bringing them into the light through dialogue, art, or play might enable Matt to explore the possibilities and perhaps find meaning that would lend coherence to his view of the world.



### **Crackle (10 Years)**

Like Matt, Crackle did not belong to a church community. He based his beliefs about life and living on science more than religion. When I asked if he believed in god, Crackle said that he did. However, as he described his encounters with god, he revealed a sense of lingering uncertainty and doubt. He thought of god in different ways at different times and his understandings of god vacillated. Sometimes he thought of god as being “huge” and other times he thought of god as being “extremely small.” He did not see god as being helpful in a way that had meaning to him, and he had been disappointed on a number of occasions because of the inconsistency with which god granted requests in answer to his prayers. When asked if god sometimes helps us, he responded, “I guess so.” He was non-committal in his answer and he expressed a doubt in god’s role in doing anything else of significance.

When asked what Crackle knew about god he said, “People believe in him, so they wrote the bible and what not to do and what to do.” He went on to describe a television episode of Criminal Minds in which a “really religious guy . . . was killing people for god.”

Crackle: He captured one of the team’s guys and . . . he kept giving the guy memory, um needles. And on his last memory, his mom was really, really sick and he didn’t want the hospital to come because she didn’t want to be treated. And then the hospital came and she said, ‘Spencer, tell these guys to go away.’ And then he said, ‘I called them and I need you to leave. You need to get treated.’ So then the religious guy said, ‘Paragraph whatever, whatever, paragraph three, page 81 or something like that. And the other guy knew the bible really well, so he said, ‘Anyone who curses mom or dad gets buried, gets buried alive or something or whatever.’

Interviewer: That’s pretty scary.

Crackle: Yeah. So the religious guy un-cuffs him and he says grab a shovel.

Interviewer: Wow!

Crackle understands the bible as being a collection of writings by people who believed in god that provide a guide for living. Upon elaboration, he presents a tension that stems from a fervid believer’s interpretation of the bible. This reading or interpretation, and the act of killing or harming another in the name of god, runs counter to Crackle’s beliefs and ways of being in the world. Perhaps he is wondering how god and religion, which is meant to help people, can lead someone to harm or destroy another human being. If this

is what he is saying, he raises a very important question that can be asked of any religious teachings.

Crackle did not believe that god created the earth, but that we evolved from primitive life forms that emerged from remnants of living matter. Crackle's spirituality and beliefs about life and living were not based on religious tenets but found meaning in humankind's relationship to nature and the environment.

Crackle: I think that people who polluted, when they die they'll see that they did something really, really wrong. They're destroying the earth when they pollute. Because you're making a hole in the ozone layer, which is making the sun get hotter, and hotter, and hotter, and then making the earth get hotter and hotter. There's an edge around the earth that stops the sun from getting through too much, but when you pollute, a hole comes. You get more, and more, and more, and more, and more, and that's what global warming is. So, if you keep polluting over and over and over and over, eventually everything will melt. All the ice in the Antarctic will probably melt. Same with the Arctic and it will flood across the entire world and kill everyone.

Crackle voiced shared concerns about global warming and the threat to life on earth due to careless polluting. He also believed that when you die, "you see parts of your life over so you can see what you did wrong." He had developed his own beliefs about being in the world that reflected a sense of seeing beyond the self to the well-being of others and the world around him. He expressed his belief in human continuance through evolution but was also aware that as a star, the sun has a finite life span and will eventually blow up; resulting in immediate freezing that is incompatible with life. He expressed deep concerns about the inevitable destruction of the planet and the life it contains. Based on his knowledge of scientific discoveries about the cosmos, Crackle understood the sun's vital role in the existence of our planet and recognized the harmonious connections between life on earth and the universe beyond.

Crackle possessed a keen sense of curiosity about the world around him and an imagination that allowed him to explore the possibilities, grappling with ideas that made sense to him in light of his learning and life experiences. During our first conversation, Crackle was asked to draw some pictures about the topic of spirituality in order to express ideas and feelings he might have difficulty expressing in words. Although it was not until the middle of the second interview that Crackle talked about his understandings and beliefs about human existence and life on earth, some of the drawings he completed

prior to this conversation mirrored the thoughts and beliefs that were expressed later. Crackle explained the features of this first drawing and revealed how his imagination was called upon when creating it.



**Figure 6.2: The Sun Going Off**

Crackle: Well the sun is going off and then it makes a circle. I just thought of Spiderman and an astronaut for some reason.

Crackle created an image that depicted his thoughts regarding the vulnerability of the space in which we live. He combined his thoughts of a comic book hero with an explorer of outer space. The combination of astronaut and super hero is interesting because while the astronaut explores that which is beyond the earth, Spiderman is the hero whose actions may serve to save the world from danger. In Hart's (2003) exploration of the secret spiritual world of children, he noted that childhood moments of wonder "shape the way a child sees and understands the world, and they often form a core of his or her spiritual identity, morality, and mission in life" (p. 53).

This awareness of the mysteries of life is part of what Hay and Nye (2006) refer to as "relational consciousness." Within this relational consciousness, children's spirituality is revealed in their awe and wonder and in their awareness and sensing of the mystery in the world around them and in their questioning and meaning making of life. As Crackle contemplated the finite nature of being, he was aware of and reflected on the connections between self, other, and universe that have value and meaning with relation

to being itself. This holistic and deeply meaningful reflection on these connections prompted Crackle to think more broadly, beyond his own being to that of the larger world. In doing so, Crackle revealed the value of living in a moral community in which respect for the earth and each other will help protect us from self-imposed annihilation. In this way, Crackle also played the part of the superhero, living in ways that served to protect the earth and by taking responsibility for his own actions in preventing further damage due to pollution.

Within this relational consciousness, the value placed on our connectedness to the earth and the universe has profound relevance to our continuance of being. For Crackle, these beliefs and values provided direction for a way of living that was not only spiritual, but ethical and political as well. Crackle's concerns for the environment and sustainable ways of life echo those of the ecologically conscious and of those who recognize the grave need to see beyond the self and the carelessness of humankind in our plunder of the earth.

In the account of her experience of the aftermath of a devastating tsunami in China, Chen (2011) attempts to depict a harmony, or universal or world spirit. Within this conceptualization is the idea that the universe and all it contains, including the earth and its inhabitants, are interrelated and are affected by disruptions to the system. We face a lot of personal and societal suffering due to natural disasters, pain, and terrors in this world. Through experiencing these realities, one develops knowledge and an attitude toward nature, others, and the world that results in the formation of one's worldview and hence, one's spirituality.

Our understanding of spirit allows us to exemplify this understanding within the structure of a cosmic order. This universal spirit is not a God-like entity; it does not restrict the acts of creation to gods or poets, nor determine the progress of human history from above. Rather, it suggests a subjective spirit that human beings possess for making improvements in facing human conditions of radical change or deviation. (Chen, p. 212)

As Crackle pondered the errors of humankind, he constructed a worldview that mirrors what de Boer (2011) terms spiritual ecology. Spiritual ecology is a way of being in the world that reflects the life ways of ancient cultures and calls us back to a way of

living that recognizes our deep spiritual connection to the earth. This awareness of our dependence on a sustainable earth and its bounty for the continuance of our being draws Crackle outside of himself to see beyond the self to a wider web of community connections. “Expanding our circle of concern to include other species, we begin to see a relationship between our spiritual condition and the planetary ecological crisis” (de Boer, p. 3a).

Crackle saw the interconnectedness between humankind and the earth and contemplated the finite nature of that being and of the lived space that we share. He valued living in harmony with nature and was deeply concerned that human pollution will inevitably lead to the destruction of the earth along with all living things. This global consciousness was reflected in Crackle’s beliefs and values that served as a spiritually based guide for living that aimed to preserve the continuity of life and to safeguard the space in which we live.

### **Summary**

In the lives of the children in this study, connections to a transcendent other and or connections to the sacred or spiritual took many forms. While some children were connected to a religious community (Amy, Quadeher, Bob, and Tony), others were not (Lucy, Matt, and Crackle). Despite doubts or lack of thought about god among some children, all these children had some ideas about god’s role in their lives. For some, god was awesome (Quadeher) or was a constant, supportive, and guiding presence (Amy). God was a guide, helping children make good decisions such as those related to maintenance of their health (Amy and Lucy). God also helped children when they were having troubles (Quadeher), or was a source strength and confidence in times of struggle (Lucy and Amy). Others said that god was friendly, nice, and invisible (Tony) and that god watches over us (Bob), and helps keep people alive, healthy, and safe (Tony).

Some children maintained a relationship with god through prayer (Amy, Quadeher, Tony, and Bob), whereas others did not use prayer and seemed to have a more tentative relationship with god (Crackle, Lucy, and Matt). For example, Crackle’s prayers went unanswered at times leaving him with lingering doubts about god’s being able to help him in times of need. However, Crackle seemed to find meaning in his connectedness with the earth and was able to see how ways of living, such as polluting,

impact the earth and all life. The ability to see the errors made in one's life when one dies seemed to be a reminder to Crackle about living life consciously aware of how one's actions affect the whole of life.

Like Crackle, Matt also doubted the existence of god. He also doubted the existence of heaven but sensed a transcendent connection with a friend who had died. Although Matt seemed to be struggling to make sense of illness and death, he was able to articulate the spiritual in a way that entailed a connectedness to life, a way of living, family, friends, and happiness. These meanings give shape to the spiritual and speak to how the spiritual is implicated in the lives of ill children. As conversations with the children unfolded, the notion of spiritual connections and continuance became even more salient as they talked about relationships and loss.

## **Chapter 7: Spiritual Connections and the Continuance of Being Jake (11 Years)**

According to his mother, Jake was a very spiritual person. She could elicit his thoughts and feelings and shared in his everyday experiences of the world, providing some insight into his spiritual understandings. When asked, Jake said he was religious and that he belonged to a church community. However, he was unable to articulate what he had learned from church and sometimes became frustrated and angry with questions about the topic.

In a telephone conversation, I had with Jake's mother months later as he was nearing the end of his life she told me that she spoke openly with him about his impending death and that he had accepted that he was dying. She told me that he believed that he would go to heaven and be with god and his cat. Jake viewed death as only a temporary separation from his mother and said that he would be her guide and would be able to show her around when she joined him in heaven.

Having a spiritual orientation can often alleviate fear or painful feelings about death. Seeing death as a transition rather than the end may also enable some to gain personal insight and garner a sense of well-being (Canda, 2001). For Jake, viewing death as a temporary separation enabled him to discuss the future and remain hopeful about seeing his mother again. As Jake approached death, his mother remained by his side. I read the spiritual in her acts of devotion to her son as she spent many of her waking hours attending to his needs. As she talked with him about his thoughts and shared in his pain, she used therapeutic touch and guided imagery to help bring him comfort and ease his journey toward the afterlife.

By the time children reach nine years of age, it is possible that some will have experienced the death of someone they know, whether it be a parent, a grandparent, or a pet. Many adults want to shield children from the pain of loss and may avoid talking with children about death. However, there is evidence to suggest that this further alienates children from the sources of information and support that are necessary in their developing spirituality and sense of self as part of the natural world (Champagne, 2008; Sagberg & Roen, 2011; Walters, 2008). Furthermore, when we shield children from death and refrain from talking about it, they are left to wonder what it is all about and

often imagine that it is worse than it is, contributing to the fear that children attach to it (Higgins, 1999).

As I spoke with the children, the topic of death emerged naturally, as we talked about illness, family, friends, pets, and the possibility of the presence of someone or something beyond the physical. The children spoke of a sense of being that transcended the physical and a continuation of spirit that endured when the physical body ceased to be. As I explored these beliefs with them, each of them related personal experiences with death and shared their own understandings of the continuation of spirit beyond the physical.

### **Crackle (10 Years)**

Although Crackle's concept of god's presence and power to intervene vacillated, he held beliefs about the continuation of life after death. He revealed that he believed in ghosts and the ability to stay connected with loved ones who have died. Crackle believed that when you die, you "go up to heaven as your normal self and then you grow wings." After being in heaven for about a year, Crackle believed that a person would come back as another baby. However, Crackle was also aware of the finite nature of being and contemplated the consequences of human actions and the impact they have on the continuance of our world and human existence, as we know it. Crackle's spirituality seemed to be fuelled by a sense of awe and wonder. While he drew from various frameworks of meaning, he was open to multiple possibilities. His spirituality also seemed to ground him in a way of living that showed concern and responsibility for the lived space we share, ensuring the continuity of being in a global and holistic sense.

### **Tony (10 Years)**

When questioning Tony about the things he enjoyed, the topic of swimming led to a story about a neighborhood toddler who drowned in her backyard swimming pool. He recalled the scream of anguish of the child's mother as he and his friend were told to sit on his doorstep a few houses away. Shielded from the vision of death, Tony and his friend were still witness to the raw emotion of the event and were affected by the outpouring of community sadness felt in the death of a child. Through this revealing, an opportunity presented itself to ask Tony about his beliefs in an afterlife.

Interviewer: So what do you think happens to people when they die, like, what happens after?



Tony: They feel sad.

Interviewer: What about where they go? What happens to people when they die?

Tony: They go to heaven.

Interviewer: What's heaven like?

Tony: I don't know.

Interviewer: No?

Tony: I would say a peaceful place.

Interviewer: A peaceful place, yeah. And who's there?

Tony: God, and all these other people . . . Emma and Jesus.

Tony believed in a continuance of life after death in which one joins god and Jesus in heaven. He saw it as a peaceful place where one is reunited with those who died before us. Like Jake, Tony saw death as a temporary separation from those who are living. He believed in heaven as a peaceful place void of the trials and tribulations of earthly life.

### **Lucy (13 Years)**

Although Lucy did not belong to a formal religious community, like the others she had some well-formed ideas about an afterlife and the continuation of self in spirit. When asked about extended family members, she revealed that her grandmother had died four years previously and relayed what this was like for her.

Interviewer: You were saying about when you're grandmother died it was really hard. Can you describe that time to me? What was that like for you?

Lucy: Ah, it was really sad and I felt lonely. I felt like there was no one there to help me through it but there was. But that was just what I felt like, and it felt really ah, frustrating.

Interviewer: Mmm hmm. What else did you feel at the time?

Lucy: I'm not sure. I kind of let it pass. I don't like thinking about it that much.

Interviewer: Is there something that could have helped at the time?

Lucy: Probably talking to someone, or being with my grandfather and grandmother, both of them, like to spend more time with them.

The conversation I had with Lucy's mother lends context to Lucy's experience and points to the importance of her family's influence in the development of her understanding and coping with death. When Lucy's grandmother died, Lucy's mother coped by shielding herself and the children from the pain of the loss. The children did not go to the funeral, and afterward all pictures of Lucy's grandmother were removed from view and she was never spoken of again. Lucy's mother said that this was her way of coping, to not talk about it, to be strong, and to just get on with things. Lucy's mother

coped with the pain of loss by forgetting. This can be seen in her hiding of the reminders of her own mother's death and in the silence that surrounds Lucy's illness and future health.

We live in a death-denying society that seems to discourage open communication about death (Walters, 2008) and what it can teach us about living. Yet it is all around us—in games and media and in our own lives. In attempts to protect their children from the pain of loss, parents might try to shield them from their own grief, perhaps leaving them bereft of role models for coping (Goldman, 2004).

Encountering death is a liminal experience that triggers a need for tools to help create a connection between immanence and transcendence. Creating or discovering such a connection is characteristic of spiritual awareness, of becoming aware of something beyond the immediate experience of seeing the body of someone they know, yet different from what he or she used to be. An open frame of reference, rituals, listening to the adults and questioning them and sharing each other's narratives are vehicles of such awareness. (Sagberg & Roen, 2011, p. 356)

Like Matt, Lucy seemed to be suffering in silence. Without adult guidance to assist her in forming a spiritual worldview, she struggled to integrate this loss as a part of life. Without such guidance, Lucy felt alone in her grief and perhaps also in the contemplation of her own vulnerability. This way of coping with illness, loss, and death is a family legacy that Lucy has adopted as well. Unable to speak the unspeakable, Lucy was sad, lonely, and frustrated. She was silenced and alone in her thoughts, trying to make sense of the loss and the sadness that she felt and witnessed around her. Eventually she got through it by not thinking about it and letting it pass. Remaining silent and avoiding reflection on the loss perhaps afforded some protection from the pain and from thoughts of potential future losses.

Despite a lack of immersion and involvement in the religious beliefs and rituals surrounding death, Lucy still had some well-formed thoughts about what happens when someone dies.

Lucy: You go to heaven, but before that, you have a funeral. Then you get buried and then your spirit goes up to heaven.

Interviewer: What is heaven like?

Lucy: It's all white. You're wearing all white and you have like a halo on, a gold halo . . . It's a peaceful place [and] you meet people there that you've already known that have passed away before that, well before you did.

Interviewer: What about the living, can we still stay connected?

Lucy: Yeah

Interviewer: How do we do that?

Lucy: Ah we, their spirit is like in your heart and you won't forget them.

Lucy believed in a continuation of life in a spiritual sense and described the spirit as “our relationships and our emotions and what you have in your mind of what your friends look like.” Spirit for Lucy was the essence of self, made up of our experiences and the things of meaning in our lives.

Lucy believed in heaven as a peaceful place where our spirit reunites with loved ones who have died before us and in the sustained connection with those loved ones through remembrance and keeping their spirits alive in her heart. Being able to stay connected with deceased loved ones by keeping them in one's heart was a unanimous declaration by twenty ten-year-olds in a study by Champagne (2008) that encouraged expression of thoughts on living and dying. This speaks to the capacity of children to find ways to feel the enduring presence of a deceased loved one in a spiritual way.

### **Amy (13 Years)**

When Amy was asked about a time she felt spiritual and connected to someone or something beyond the physical, she shared her experiences of her relationship with her dog, Panda.

Amy: We were so close to each other, and I grew just to love her so much and I had to put her down. I know lots of my friends have had worse tragedies—but losing her was just really sad. I knew that when she died she was going to a good place and god was going to look after her and that she was protected in the safest place she'd ever be and that nothing bad was ever going to happen to her again. And one day I would see her and we'd all be together again. She's never too far away, and if you just really miss her and need to talk to her, then just talk to her and she'll listen.

This sense of presence was one that was comforting to Amy. She was reassured by Panda's presence and that she would be there and willing to listen. She also talked about her present connection with her grandfather and the fact that she would maintain this strong connection with him even after he dies. This sense of feeling a supportive

presence speaks of the spirit that dwells within a meaningful relationship that continues to endure despite physical separation. These connections served to comfort and guide, leading to a widening of Amy's network of support. These connections not only supplemented Amy's sources of support, but they were always present as she carried them with her wherever she went.

### **Quadeher (13 Years)**

When asking Quadeher if he ever sensed the presence of god or a force or energy around him he reported that he had. When probed, Quadeher revealed that he sensed the presence of his Uncle Bamps and that this was a comforting feeling. In a later conversation with Quadeher's mother, she revealed that Uncle Bamps was Quadeher's great grandfather who had passed away when he was quite young. As a toddler, Quadeher visited his great grandfather every evening and watched Jeopardy with him. This sense of spiritual connectedness remained with him from a very young age into his teen years and continued to bring him comfort despite his great grandfather's prolonged physical absence. This speaks to the enduring quality of this spiritual connection that has remained present over time.

### **Symbols of Spiritual Connectedness**

#### **Bob (9 Years)**

While asking Bob about members of his family he revealed that his grandfather had passed away two months previously. He said that he was close to his grandfather and that his death had been difficult for him. As we looked at pictures in a photo album from when Bob was first diagnosed, we came across one with Bob in bed with a cloth on his head with his grandfather and his cat asleep beside him. When asked what comes to mind when looking at this picture he remembered his grandfather as being playful.

Interviewer: So how do you stay connected with him, like, in your heart?

Bob: Just remember him.

Interviewer: Just remember him, yeah. . . . Anything else?

Bob: Go to my grandmother—visit her.

Interviewer: Yeah, go and see her, remember him and

Bob: She's only maybe about ten minutes away.

Interviewer: So very close by . . . so they've been a very big part of your life, sounds like.

Bob: [Nods affirmative]. We've been going there quite a bit because she has to get a whole bunch of work done but she can't do it all by herself anymore.

Interviewer: And so do you go over and help as well?

Bob: Sometimes.

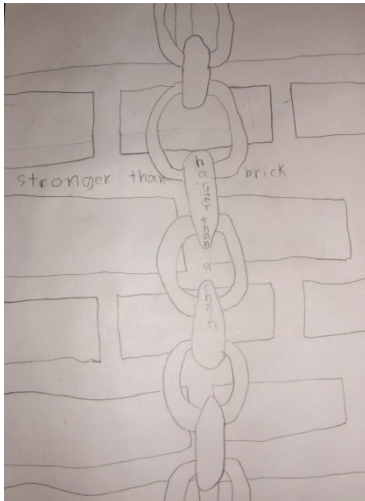
Interviewer: Sometimes . . . good . . . what kinds of things do you do to help her?

Bob: I like entertaining her by walking on the stilts.

Bob stayed connected to his grandfather by going to his house to visit his grandmother. Being with her and being in his home, surrounded by his things seemed to help him to feel close to him. Walking on the stilts that his grandfather made gave Bob a sense of accomplishment while he entertained his grandmother. As he walked on the stilts, there was a sense of connectedness to his grandfather that reminded Bob of his grandfather's playfulness.

When children encounter death, it becomes clear that grief involves relational and systemic perspectives. The need to re-member, taken in its basic meaning of putting together as a whole again, gets new meaning. It is not a matter of just 'letting go' and 'moving forward,' but of establishing some way of understanding oneself in continuity with the deceased. (Sagberg & Roen, 2011, p. 357)

When asked to draw a picture about his connection to his grandfather, Bob created the following illustration.



**Figure 7.1: Feeling Connected to Grampie**

Bob described his feelings of connectedness to his grandfather as being “stronger than a brick” and “harder than a chain.” As Bob walked on the stilts, he honored his grandfather's memory. The stilts symbolized his grandfather's playfulness that remained

a part of Bob, and as Bob walked on the stilts, he was elevated toward him feeling a connection that was enduring, despite his physical absence.

There is a part of grief that absolutely involves a departure, a physical absence, a loss, and ending to a relationship as it once was . . . While simultaneously letting go of the deceased, the bereaved are also finding ways to remain connected, to redefine their relationship with the deceased (Moules, 2009, p. 64).

### **Crackle (10 Years)**

Crackle also sensed a connection to a transcendent other, mediated by an object that held special significance within the relationship. When asked if he ever felt really close to someone or something, Crackle revealed a spiritual connection that was represented by an object of comfort.

Interviewer: Have you ever felt really close to someone or something? Tell me about that.

Crackle: Hmmm, well I had a blanky when I was little and my grandma made it, so and then she died only like two, or one or two years ago so...

Interviewer: Mmm hmm

Crackle: She made it herself because she was an artist like me, and she knits things. And then she died, and I kept the blanky ever since.

Interviewer: Mmm hmm

Crackle: Yeah, ever since I was little.

Interviewer: Wow, so you keep that blanket with you.

Crackle: Yeah, just to remind me of her.

Crackle forged a spiritual connection to his grandmother through the blanket that she made for him. The blanket was a concrete symbol of that connection, a symbol of warmth and comfort that also told of the artistic talent that his grandmother passed on to him. Although he did not feel his grandmother around him, he believed that she was “having a peaceful life in heaven” and he was able to remain connected to her through symbols of significance that served as reminders of her being part of his life.

A child’s personalized spirituality is built upon symbols of meaning that concretize the child’s spiritual experience and give a tangible location for the divine (Reimer & Furrow, 2001). This is similar to Winnicott’s (1971) theory of transitional objects and phenomena where an infant maintains a felt presence of the primary caregiver through objects of representation. These associations are needed in order to sustain the feeling of connectedness in the growing awareness of self as separate from the

other. For Crackle, the blanket was a symbol of the connectedness with his grandmother that bridged the gap between them, transcending the physical to a felt sense of the spiritual. This served as a reminder of how she is part of him, her love for him, and of the meaning in their relationship.

### **Bob (9 Years)**

Bob also spoke of objects that had significance with relation to the spiritual and coping. This response was prompted by a question about what he had learned about having cancer and if he lived differently since having cancer. In Bob's response, he began talking about sleep routines and patterns that have significance in relation to his illness experience.

Interviewer: What would you say you learned about having cancer, like what you learned about yourself or what you learned about life? Do you live in a different way?

Bob: Well I turn my pillow around a lot of the time, and at the cottage, I sleep at the wrong end of the bed.

Mom: I think what she means is do you do things differently or care about different things now.

Interviewer: Do things matter more or are they the same?

Bob: Things are good. I like my stuffies a lot more. I have a whole bunch at the bottom of my bed and I sleep with one.

Interviewer: What does that do for you?

Bob: Helps me get to sleep.

Interviewer: What is it about that? What does it feel like?

Bob: Well I don't really like having my arms like this in bed. It doesn't feel normal to me because I've been sleeping with my stuffies for a long time.

Bob was only five-years-old at the time of his diagnosis but he remembers how he felt and what helped him get through this tough time in his life. When asked if he thought about life any differently since being diagnosed with cancer, he revealed that there have been changes in his bedtime and sleeping rituals and the fact that he likes his "stuffies" a lot more now.

Bob's reference to pillows and wrong ends of the bed relate to his comfort with sleeping. Memories of the physical discomfort imposed by tubes and equipment accompanied by fears of being woken from sleep for a needle still linger. Since having cancer, he realized that he likes his "stuffies" a lot more now. Perhaps they symbolize comfort and safety, giving Bob a tangible sense of a protective presence. His "stuffies"

were watchful keepers, providing safety and consolation. As Bob wrapped his arm around his “stuffie,” he drew reassurance from its presence that seemed to enable him to find refuge from discomfort and fear.

Interviewer: There’s something in that stuffie that makes you feel a certain way. What is that? I’m trying to figure it out? What is it?

Bob: Well every night I have um, what’s that, is it fake grass or something? The thing we use for projects that grass thing on a stick. I have it on my bed. I swish it around right above my bed for catching my bad dreams.

Interviewer: So it catches your bad dreams. Can you tell me about a bad dream you’ve had?

Bob: Well one time I was at my cottage and there was a whole bunch of leeches on the floor; and it just scared me to death.

Interviewer: Mmm hmm. . . . So you have this grass thing above your bed that helps take away the bad dreams. . . . Does it help?

Bob: [Nods affirmative]

Interviewer: Yeah

Bob: Because I haven’t had a bad dream for a while.

Once again, Bob referred to difficulties with sleeping and revealed that bad dreams have interrupted his sleep. Although he said that he has not had a bad dream in a while, one such dream was about leeches all over the floor. This scared Bob “to death,” mirroring the threat of the taking of blood that has been such a routine and frightening aspect of his treatment. As a means of combating bad dreams, Bob held trust in his dream catcher that afforded him protection from invading nightmares.

### **Tony (10 Years)**

Tony also talked about having bad dreams and he too used a dream catcher that he said captured all his good dreams. For both boys, this concrete object was a symbol of protection, one that is a common spiritual symbol in North American First Nations culture. Symbols and objects of meaning that connect children to the transcendent dimension enable them to experience a sense of unity with that which is beyond the physical. Born from an innate need to feel a sense of comfort and safety, these objects become the sign signifier that enabled the boys to reach beyond the tangible to the transcendent (Cavalletti, 1992). Symbolic representations can serve as a medium through which spirituality can be experienced and explored and can also enhance spiritual connectedness with self, others, and the transcendent (Moriarty, 2009).



As the boys lay down for sleep, a dream catcher symbolized protection from the terrors of the night. Terrors perhaps gathered from their daily experiences not yet processed become the fuel for the nightmares that invade the mind and disrupt a peaceful sleep. Negative energy harnessed and harbored form images of fright behind sleeping eyes. Fearing for their safety or perhaps even their lives the boys found solace in their beliefs in a shared symbol of meaning. Belief in the sacred power of the dream catcher enabled the boys to sleep soundly in the knowledge that they were safe. Allowing only good dreams to pass, the dream catcher ensnared the bad dreams, banishing them at daylight, affording protection from the unbidden horrors of the night. Their belief in the power of spirit to transcend the earthly and intervene between good and evil was embodied in the dream catcher, its divine protection enveloping them in a cocoon of safety.

## **Chapter 8: The Spiritual in the Playful**

Activities that children find meaningful can also potent vehicles for spiritual expression and transcendence. Play and having fun were consistent themes within the children's narratives that seemed to lead to an overall sense of happiness and well-being. Play enables children to experience the wholeness of self and express the meanings that arise from being in the world. Free flowing and fluid, play draws the child into this ludic experience. Time stands still as responsibilities are forgotten, affording reprieve and freedom. Caught up in the flow of play, the child experiences self as whole and integrated with their surroundings, expressing authentic spirit as they become one with self and all that is other.

### **Kicking off the Constraints of Illness**

#### **Crackle (10 Years)**

Throughout our conversations, Crackle often referred to his love of soccer and his joyful experiences of playing the game. Animated, he lit up with excitement as he talked about his favorite sport, revealing a passion that was palpable. When asked to describe an experience in which he felt that everything was wonderful and perfect, leaving him feeling good inside, he explained that he felt this way when his soccer team came in second overall in a tournament. He felt a sense of achievement that was memorable and meaningful that spoke of the glory felt in winning and demonstrating the abilities of his team in out-playing the others. He expressed a sense of mastery within this domain, often voicing confidence in his talents and abilities.

Play is an expression of a child's creative spirit in which the child can discover the self and experience spiritual transformation in the joy and spontaneity that emerges in the free flowing dimensions of play (Bhagwan, 2009). Maslow (1999) also recognized sport and physical activity as a source of spiritual experience, and even 'peak experience' in which a person experiences unity between self, other, and world, filling them with a sense of intense happiness and well-being. Moriarty (2011) claims that sport connects children with all spiritual dimensions, including "consciousness through their bodily enjoyment, relationality through friendship and teamwork, roadmap in the values that flow from participation, and identity as having a sense of competence and belonging" (p. 281).

Although there were many things revealed about Crackle through his love of soccer, there were certain things that resonated with meaning that point to his coping with CF.

Crackle: What do I like most about soccer? Probably running around and kicking it because in most sports you don't really get to kick anything. So, it's fun to kick it.

Interviewer: It feels good to kick that ball.

Crackle: Yeah.

While engaged in playing soccer, Crackle was drawn into its to-and-fro movement in which the seriousness of existence fell away. Within this time and space, Crackle escaped the realities of life's responsibilities and lost himself in the experiences of wholeness and freedom afforded in play. Despite this removal of self from the responsibilities of life, "play itself contains its own, even sacred, seriousness" (Gadamer, 1975/2004, p. 102) in which Crackle's intentions toward serious things were revealed.

When asked what he liked most about soccer, Crackle talked of his delight in the physical act of running and kicking something. In biblical verse, the figurative meaning of the word "kick" is to "complain," "protest," or "rebel against" (Harper, 2001-2013). The restrictions of Crackle's illness gave him good reason to protest and rebel. Although he did not complain much when he was told to do his treatments, he remained fettered by the persistent reminders of responsibility and the threat of anger if he did not comply in a timely fashion. As Crackle kicked the ball, he was able to protest and rebel against the forces that bound him. There was a felt sense of power over the ball, an ability to manipulate it with force, releasing the energy that dwelled within him. There was a freedom of movement and a satisfaction with connecting with the ball, seeing it fly through the air toward its target. He felt fulfillment in the transfer of energy from his body to this object as he directed it at his will with gusto and the promise of the possibility of triumph.

Play is a phenomenon that has existed across cultures and has endured over time. A universal, existential phenomenon, play is fundamental to our ontological constitution and is an unadulterated form of self-representation (Gadamer, 1975/2004). Although we might recognize play when we encounter it, and are assured of its existence through our own experiences of it, we often fail to see the symbolic significance in its representation of life. Within a view of play as frivolous, without product or purpose, we fail to

recognize the relationship between play and the serious matters in life (Fink, 1968, 1974; Gadamer, 1975/2004). Much of conscious human action is directed toward something with a purpose that aims to reach a meaningful end goal. While play takes us away from the seriousness of everyday life, it also provides a space and time for the expression of being in which object and action become symbols that represent the meanings in a given life (Fink, 1968, 1974).

The multiple meanings Crackle derived from playing soccer became obvious as we talked about a variety of topics. As the following quote illustrates, Crackle made connections between his positive outlook and an experience with playing soccer.

Interviewer: Yeah, you seem like a pretty positive person.

Crackle: Yeah [with certainty]. Really, yeah.

Interviewer: Really positive outlook, you know.

Crackle: Yeah. Like today at recess, I was playing soccer and there was like five minutes left of recess, and I didn't think I was going to get a goal in soccer because I was in defense. And all their other players were pretty good, and their goalie was pretty good. But then I get the ball, right close up to the net. I go up to the goalie, fake him out, get a goal. Sooo, that was helpful. That was nice because I didn't get a goal this season in soccer because I'm always goalie, because I'm a really good goalie. And I'm either on defense...one time, well a few times, I might be a mid-fielder or forward. Yeah. Like if I have a whole bunch of energy, I'll be, like, I'll be on forward or mid field, so . . . yup.

As Crackle described his experience of getting a goal in soccer, he revealed a belief in himself and in possibilities that enabled him to initiate action toward his goal despite the odds against him. He moved toward the obstacles with an ease and a sense of self as capable of overcoming. It was the possibility of success and the unpredictability of the game that drew Crackle into its contest. It was in this trying of self and being tried, the mastery of action and being mastered, that created the allure of the game itself, keeping Crackle enthralled and caught up in its freeform flow. "Play does not have its being in the player's consciousness or attitude, but on the contrary play draws him into its dominion and fills him with its spirit. The player experiences the game as a reality that surpasses him" (Gadamer, 1975/2004, p. 109).

Hyde (2004) makes the connection between play and the expression of spirit and meaning in life when he speaks of ontological awareness. Ontological awareness that is experienced during play is the ability to experience the world with the whole of one's

being. In this respect, perception is direct, experiential, and concrete and engages the mind, body, and spirit with the whole of the activity in which one is involved. There is no separation of self or of self from other or activity. In such a way of knowing, there is a feeling of being “at one” with self and object or other, a sense of unity that integrates the person with the whole of their experience and its expression (Hyde, 2004).

Although Crackle found freedom in play, there were also restrictions and rules that constrained him that mirrored his everyday challenges with his illness. As a goalie, Crackle was restricted in his movement. He was unable to run the entire expanse of the field with the others and kick the ball, feeling the experience of exhilaration in the possibility of getting a goal. He was left to watch from the defensive zone while protecting a vast space, waiting for his chance to connect with the ball and be an active participant in the game. This restriction of movement and confinement of body in space dictated by game rules limited Crackle’s opportunities to kick the ball and to be immersed in the to-and-fro movement of play, mirroring the perpetual restrictions and responsibilities encountered due to his illness.

In the telling of his story, it became apparent that Crackle’s illness imposed the limits on his body that hampered his ability to achieve his goals. He mentioned times when he lacked energy that prevented him from enduring the rigors of offensive play, and it was because of this that he was relegated to goalie or defensive positions that curbed his freedom of movement. Despite the betrayal of his body in his intentions to participate in offensive play, he continued to maintain a sense of self as effectual and was able to recognize his worth as a good goalie and a valuable member of the team. His need to protect this vast space mirrors the responsibilities of protecting his health and the bodily space in which he dwells by adhering to the treatment regime that keeps him well while others his own age continue to play. As he remained restricted by the rigors of treatment that prevented his engagement in play, he longed to be free to participate in that which brought him such meaning and happiness.

Despite the rules and restrictions dictated by the covenants of illness and game, of which Crackle was bound, he chose to overcome these constraints by pressing forward, kicking, and rebelling against the imposed shackles. In these actions, Crackle revealed not only his quest for freedom from the responsibility and rules that bound him

but also his belief in himself as capable of overcoming. In the descriptions of Crackle's experiences of playing soccer, there was an inherent sense of power and freedom. In his effort to explain how he had a positive outlook on life, Crackle shared a story about his experiences of playing soccer. This story speaks of his feelings of mastery and his sense of self as transcendent with a capacity to overcome obstacles to reach his desired goals. He also saw himself as a valued member of a team of others who worked together toward a shared goal. For Crackle, there was also a sense of transformation and transcendence in the act of playing soccer. Finding his passion, Crackle was animated. He became powerful, furnished with protection that could even mitigate risk and facilitate health and well-being for a lifetime (Blumenkrantz & Hong, 2008).

While attending a camp for young people with cancer, Laing (2012) recognized something happening within the children as they became caught up in play. She described a young girl as she climbed to great heights despite her trepidation. Strapped in a swing, she was full of anticipation. Then "the swing was released, sending her on a giant arc back and forth through space and time, her face awash with exuberant bliss" (p. 3). Laing recognized something at play in play that was difficult to pin down. Although she wanted to figure out what it was, she had difficulty naming it. Words she used were "surrender, transcendence, giving-over, and vulnerability" (p. 5) but still were inadequate for describing what she saw.

Child development scholars have long described play as the developmental work of children. It is a natural form of expression and a medium in which children work through life issues and learn about themselves, others, and the world around them (Lifter, Mason, & Barton, 2011). Because children are not always able to articulate experience through language, play becomes an existential mode of expression that encourages imagination, freedom, and spirit that enables them to throw off constraining inhibitions and restrictions (Oaklander, 2001). Play enables expression that provides "insight regarding the meaning and purpose of life within the context of a chronic condition." Play, as in therapeutic play, has also been known "to alleviate spiritual distress" among ill children (Fulton & Murphy Moore, 1995, p. 228). In attempting to understand childhood spirituality and the meanings children give to their experiences of illness, play becomes a window through which to gaze upon this elusive part of their being.

## **Wrestling with Illness and Fighting for Breath: Inspiration and the Inner Spirit Amy (13 Years)**

Amy also described her positive outlook on life through her telling of experiences with play stories in which transcendence of self over a wrestling opponent mirrored her fight against her illness. Amy's wrestling enabled her to articulate symbolically the challenges she faced while living with CF.

Interviewer: Do you think illness gives people a different outlook on life, I mean you have CF; does it give you a different outlook on life?

Amy: I sometimes look at it as a challenge that only I'm facing and I'm going to beat it

Interviewer: Mmm hmm

Amy: [It's] like when I'm ready to give up in wrestling. When I'm like, "I should just give up," I can't. [If] I'm having a hard time breathing or it's getting rough for me, I'm like, "No, I'm not giving up." I'm going to fight it, and I'm going to try my best. And if in the end I lost, then I'll remember what I did and try to fix it. That's how I think about CF. I'm not going to let it beat me. I'm going to fight it and I'm going to beat it.

Metaphor and analogy are forms of language that can be used to articulate experiences that are important but perhaps difficult to explain. They allow us to see more deeply, where the underlying meanings reside and illuminate the spiritual that is often hidden in the everyday language of experience (Parks, 1986; Sontag, 1990).

Amy found meaning in her illness by embracing the symbolism of wrestling and was able to share this meaning with others in a way that revealed something of her inner self. Grappling with an opponent that threatened to pin her down and deprive her of breath symbolized the daily struggle against a disease that never lets up. Breath and breathing are related to the spiritual. The word spirit originates from the Greek word *pneuma* and from *spirare* meaning "to breathe" (Harper, 2001-2013). Breath like spirit is a vital principle for life—moving unseen, animating, and enlivening. Amy's struggle for breath was not only a fight to maintain the mechanism essential for life but was also a calling forth of an energy that breathed life into her everyday actions, animating her with the strength to meet the daily challenges of her disease.

Amy knew she could not give up and was determined to try her best in the fight against her disease. She found the strength to overcome the everyday restrictions of her illness and found meaning in her daily fight. Even if she was not successful in preventing exacerbations of her illness, she saw the value in learning what she could do differently

to avoid them in the future. She lived with awareness, reflecting back on experiences of illness as a reminder of the things she needed to do to stay healthy.

### **Art as Source of Meaning**

#### **Jake (11 Years)**

Although the creation of art may not be considered play, many children engage in this activity as a form of play. Like in play, art calls on the imagination to create a rendering of the lived world that may not be easily expressed in words, and in the creation of art, more is revealed than one might have intended in its making (Gadamer, 1975/2004). As I sat with Jake, he continued to draw and paint while we talked. He used his body continuously in his creation of art as he responded to my questions, sometimes displaying frustration with the outcome of his work. This embodied expression through art enabled some of the hidden aspects of life to be revealed.

As well as missing a lot of school because of his cancer, Jake claimed that many other things had changed as well. Although he was at a loss to explain explicitly what had changed, he relayed the feeling that cancer had disrupted his life in a big way. When I asked him what was going on that day, acknowledging that he was having some tests and scans done, he avoided the question. He immediately became exasperated with his drawing, tearing out the page in anger, crying, “Aah . . . it doesn’t look right.” Upon beginning another, he continued to get frustrated, lamenting that it still was not right, again tearing the page from his sketchbook. He agreed that he was mad and attributed his anger to his drawing and his inability to get it “right.” As he acknowledged his anger, he continued to draw, and with a deep intake of breath and a verbal calmness stated that his latest attempt was “close enough.”

As I inquired further about the things that made him mad, Jake became silent and continued to draw. He then began to scribble vigorously over his drawing, again displaying an anger that was palpable. In the margin of one of the aborted drawings, he wrote “good” and a number of check marks followed by the letter “x” repeated down the page. When asked what they meant, he stated that they were “failed attempts.” Given the previous failed attempts to treat his cancer effectively, the parallel expression of this through his drawing speaks of the frustration and uncertainty that could not be conveyed in words. As he anticipated the results of the last two days of tests and scans and all that



he had already been through, his anger deepened, beset by the uncertainty and vulnerability that was his life.

When I reflect upon these interactions with Jake, I cannot help but wonder how he made sense of what was happening to him. In his expressions of anger and frustration, I sensed that he was also experiencing profound inner turmoil as he contemplated the uncertainty of his illness and the meaning it had in his life.

Spiritual distress and spiritual crisis occur when individuals are unable to find sources of meaning, hope, love, peace, comfort, strength and connection in life or when conflict occurs between their beliefs and what is happening to them. (Anandarajah & Hight, 2001, p. 84)

Feelings of spiritual distress are common among children with end-stage cancer that relate to an inability to find meaning in illness, life, and death and in their grief for present and future losses (Foster et al., 2012). In Jake's embodied expression through art, something primal was revealed. Unspoken frustration and uncertainty found expression in a blackened mass across the page and within it a truth of his reality. Within this expression, there also seemed to be a transformation—a release, a realization, and perhaps a beginning acceptance of what was.

In retrospect, the use of art as a form of play may also have been a way of escaping his thoughts about illness and its meanings. As he engaged in the creation of his art, he was able to create a space for himself in which he was better able to express and manage emotion. Although Jake told me that he could play and listen at the same time and responded readily to questions that had meaning to him, at times I sensed that he was also using his art as a means of diversion. Using play as a means of escape from thoughts of illness was also a common occurrence among the children.

### **Play as an Escape from Illness**

#### **Tony (10 Years)**

Many of the children spoke of how they used play as a means of spending time that helped them to ignore or forget about what was going on around them. Tony was one of the children who emphasized play as integral to his sense of well-being. He became quite animated when he described his experiences of play, and it was obvious that play was an essential and meaningful part of his life. For Tony, play was also used as an

escape from the monotonous and sometimes painful physiotherapy treatments he endured on a daily basis.

Tony: But when me and my dad are watching television, I don't even remember.

Interviewer: Yeah? You don't even remember what?

Tony: Well if he's actually doing it or if I'm playing Ape Escape.

Interviewer: So watching, doing that, the Ape Escape helps you to keep your mind off your

Tony: paddles

Although Tony did not resist requests to adhere to his treatments, he lamented that the paddles were sometimes painful. Although his father reported that Tony became distracted by television and games and required reminding to stay on task, Tony viewed these distractions as useful in coping. As he moved through a virtual world of characters, Tony was in control. He was lost in time and space, as he became the kid named Jay who battled the evil monkey who tried to beat him with his robot. Tony was able to escape this beating easily however by knocking the monkey's two arms off and then by hitting his chest three times. "Power as autonomy in the face of mundane reality is immediately related to play. The ability to experience power, albeit in illusory ludic space, is one of the greatest attractions of play" (Lindquist, 2001, p. 14).

In this virtual world, Tony was powerful as he mirrored the actions that would be required to escape the paddling of his own chest. Instead of resisting the physiotherapy treatments he knew he needed, he was able to thwart the evil monkey to avoid being beaten. As his father paddled his chest, he was able to escape the discomfort of the "beating" by knocking off the offending arms and by hitting the monkey's chest instead.

Within this play, Tony was afforded the opportunity to assume an identity that imbued him with a power he did not possess in "real life." Animated and infused with strength, he battled the enemy, feeling a power that moved him beyond his body to a sense of transcendence. In this simulated environment, players are able to "facilitate imaginative engagement in spiritual quests, battles between good and evil and challenges to prove their collaborative spirit and personal merit" (Yust, Hyde, & Ota, 2011, p. 2). However, while virtual gaming may be an avenue for children's exploration and expression of the spiritual, there are warnings of the dangers in overuse of this form of play at the expense of other forms of play and learning. Excessive use of gaming as a

means of escape from reality also relates to children's reported feelings of sadness or boredom with life (Yust et al., 2011) leading to the concern that over-involvement in virtual realities may inhibit rather than facilitate spiritual growth and learning (Yust et al., 2011; Bhagwan, 2009). However, this was not evident through Tony's descriptions.

### **Bob (9 Years)**

Like Tony, all of the other children talked about how they used play and other pleasurable activities to distract them from the boredom and the experience of missed time with their friends. According to Bob, what made his hospital stay more bearable was the myriad of distractions in the form of technology. He was able to enjoy the luxury of a flat screen television and exclusive use of gaming systems that he did not have at home. He would send his father to get video games that would relieve him of the boredom, making time pass more quickly.

In the autonomy of play action there appears a possibility of human timelessness in time. Time is then experienced, not as a precipitate rush of successive moments, but rather as the one full moment that is, so to speak, a glimpse of eternity. (Fink, 1968, p. 21)

There is timelessness in play in which there is a "sense of unity, oneness, or wholeness with the activity" that exemplifies the relational aspect between self and other that transcends time and self-other dichotomies (Hyde, 2004, p. 22). This sense of unity or oneness or "awareness-sensing" is an integral component of childhood spirituality (Hay & Nye, 2006).

During the initial diagnosis and treatment stage, Bob was inundated with information. In his shock and weariness, he chose to use the technology around him to help remove himself from his surroundings and situation.

Bob: I didn't really understand it because most of the time I was sleeping.

Interviewer: I remember you saying the last time I was here about when the doctors would come in you'd turn the television on.

Bob: Yes

Interviewer: And drown them out, tune them out.

Bob: Well I would drown myself out so I wouldn't have to listen to the conversation.

Interviewer: Ahhh [yes], and what was it about that you didn't want to listen to?

Bob: Well I just don't like listening to things.

Interviewer: About yourself or . . .

Bob: I don't like listening to anything period. Basically, I didn't want to hear them talk about things that are going wrong.

Interviewer: So that was a way of not hearing what you didn't want to hear.

Bob: And my mom would turn the television off.

Interviewer: So you would listen then to what was going on?

Bob: Well I would kind of block it out of my head unless they're asking questions.

Bob coped with the initial realities of his illness and treatment by insulating himself from what was being said around him. He created a space where he felt safe and could escape in the presence of others who were known to be the bearers of bad news. He drowned himself out by filling his head with distractions and was able to block out what was being said about him. Even though his mother would make him turn off the television and listen, he found other ways of occupying and protecting himself to avoid hearing what they had to say.

Donning an impermeable cloak, Bob was enveloped in a "cocooned space" (Hyde, 2008) where the stark realities of illness were prevented entry. It was a space in which to dwell—cut off from the talk that was about him. He created a safe place that was his alone. Perhaps the adults around him were oblivious to his needs for this space, a place where he could feel at home, protected from the grave realities of his illness and the suffering it engendered. Forcing him to face these realities in that moment was perhaps a violation of this private space and a disruption of the lived experience of the sacrosanct.

When asked what he would say to help someone else who was dealing with cancer, Bob relayed that he would tell them not to think about it. Bob's way of avoiding thinking about cancer and what it meant was to use television and video games as a means of distraction.

The play world does not form a curtain or a wall between us and all that is around us, it does not obscure or hide the real world. Strictly speaking the play world has no locus and duration at all in the reality-complex of space and time—but it possesses its own internal space and time. And yet again, while playing we consume real time and need real space. But the space of the play world never merges into the continuum of space that we inhabit

in real life. The same is true of time. The curious interplay of the dimensions of reality and the play world cannot be demonstrated in any other known model of spatial and temporal relations. (Fink, 1968, p. 24)

Although retreating to this “cocooned space” did not obscure reality, it served to block it out for a time so that Bob could deal with it in his own way. In this space, illness was forced out of existence. Bob was able to escape to this place, finding a sense of normalcy in a world turned upside down.

He told me that having to listen to what the doctors had to say was also “a little boring.” It pierced through his place of forgetfulness about illness, forcing him to acknowledge what was dreaded. He did not want to hear if he had to have needles. He preferred to have his parents relay this information to him, saying that then he would be able to take his anger out on them. He was unable to express his anger toward the doctors and nurses but he felt safe and justified doing so with his parents. When his parents would tell him things were going wrong or that he had to have a needle, he could “yell at them,” “try and annoy them,” and choose to “not listen.” This was Bob’s way of safely expressing his anger and exerting some control in a situation where he was given little power or choice.

Play, as an existential mode of being in itself, afforded children a means of transcending the challenges of illness and of seeing the self as capable. Play was a vehicle for creating space in which children felt power and was a means of escape from the mundane and sometimes intrusive aspects of illness and its treatments. This creation of space and use of time enabled children to suspend awareness of real time and their environments in order to become at one with themselves, others, and create meaning in the illness experience.

## **Chapter 9: Nurture of the Spiritual within Family and Community**

Although there were many aspects of illness that resulted in a disruption in children's relationships with self, other, world, and the transcendent, there were also experiences in which illness led to a greater understanding of self and life and to a strengthening of relationships with those around them. With attention to stories of the impact of illness on relationships with others, we can glean a better understanding of the spiritual as it is manifested in children's everyday experiences within the family and community.

### **Experiences of the Spiritual within the Family**

The family is the primary source of information for children about life and ways of being in the world. Rites, rituals, traditions, and symbols of meaning are passed from one generation to the next as a means of conferring family beliefs, values, and stories that provide spiritual guidance. Families are also the primary source of mirroring in which children can see themselves as seen by the other before going out into the wider world on their own. Family is hopefully a place of belonging in which children look for love, acceptance, and sense of self as an individual of worth. In the following section, the presence of the spiritual within familial relationships and the importance of family are explored.

### **Nurturing an Authentic Spiritual Identity**

**Amy (13 Years)** □ Throughout Amy's illness narratives, there was a strong theme of god and the spiritual as a source of meaning making in her life. Although Amy incorporated the teachings of her religion into her guide for living, she also resisted blindly following all aspects of church doctrine.

Amy: Some of the things that they say in our church I don't believe . . . Like they say not to do yoga because every yoga pose is worshipping a god, worshipping a pagan. I don't believe that. It's exercising and it's getting your body healthy and stretching, so I'll still do it. If it's a sin, then I'm sorry, but I want to exercise and keep healthy . . . I'm sure he [god] would understand . . . I'm not going to do every single thing because then you're not free . . . So I do pray, and when I do make sins, I ask him to forgive me and I'm still going to do my yoga.

Amy struggled with the contradictions of church doctrine with regard to her intentions to be healthy. To Amy, not all beliefs held by her church made sense, and she recognized

the need to critically analyze these teachings and reject those that did not have meaning in her daily life. Contemplative practices such as yoga, prayer, and meditation are embedded in many religious traditions and have been known to contribute to spiritual development (Jennings, 2008). In ignoring church rules, however, Amy harbored some lingering doubts and related remorse. Was doing yoga a sin in god's eyes? Was she defying god or were her intentions only to do what was right—for herself and for her health? As she grappled with these contradictions, she settled on the idea that god would understand her need to be healthy and that god would forgive her, even if yoga were a sin. For Amy, the belief in an understanding and forgiving god helped to alleviate feelings of guilt and enabled her to act in accordance with her own established beliefs.

What is surprising here is the level of maturity in the analysis and negotiation skills needed to come to these understandings. How did Amy arrive at this way of thinking? As Amy tells her story, clues to the origin of her views are revealed in observations of the relationship between Amy and her mother. For example, when asking her mother for clarification of the word “pagan,” she revealed that yoga, as a sin, had been a topic of discussion between them.

The need for Amy to clarify her understanding points to the importance of parental guidance in reconciling conflicting information and messages that children receive from the world around them. The answers Amy's mother gave her then guided her in forming her individual identity in the context of her health and religious teachings. Amy was encouraged, and thus given the power to exercise free will that enabled her to maintain a sense of self in the midst of mixed messages about how she should behave and who she should be. This freedom to choose and to think for oneself was a family value that had become part of Amy's being. This thread, woven throughout Amy's stories, told of her capacity to think critically and reflectively while relying on voices of reason to guide her in the ongoing development of self in relation to others and the world.

Spirituality is woven throughout one's whole being. It is embodied in expressions of our understandings of the world, the attitudes, beliefs, and values that we hold, as well as our emotions, intentions, and behaviors. These aspects of self are constantly in flux as we attempt to make sense of our lives and understand who we are as individuals.

Dialogue about life and living enable us to create meanings that are congruent with deeply held values and beliefs and prompt us to live a spiritual life that is true to the commitments we hold (Webster, 2005).

Amy's way of critically analyzing culturally prescribed meanings to fit her own life allowed an authentic way of being. By creating her own meanings and freely choosing actions she was exhibiting an "authentic spirituality" (Webster, 2005) that resisted unquestioned conformity. This enabled her to form a sense of identity separate from but related to the cultural and religious community to which she belonged. Children are active meaning-makers in their construction of a personal worldview. Rather than drawing strictly from the religious or cultural context in which they were raised, children tend to choose meanings from multiple frameworks in the creation and expression of their spirituality (Hyde, 2008). As human beings we are free choosing meaning-makers, and although we are embedded in cultures of understanding, we are not necessarily determined by them (Webster, 2004).

Recurring themes in Amy's discussions about god were that of reward, punishment, and blame. These beliefs are important to note because they point to her inner struggle with regard to her own behavior and striving to live a life according to the teachings of her religion. While the assignment of blame for illness on the ill person served to keep the onus of responsibility for her personal health in her own hands, it also left her open to further questioning of god if her health deteriorated despite her best efforts to maintain it. Given that Amy related the cause of illness to a person's action or inaction, how did she make sense of having cystic fibrosis? Where did she find the strength to persevere and maintain her positive outlook on life, especially when faced with the everyday burdens of her illness?

Toward the end of the final interview with Amy I read her a poem called "Faith" written by a former patient at the IWK who had cancer (Joyce, 1990) (See Appendix G). This teenage girl was questioning god about the meaning and purpose of her illness and was seeking to understand the reason for her situation. When I asked Amy what she thought this girl was saying, she re-iterated her previous thoughts and revealed further reasoning for god's purpose in illness.



Amy: God doesn't give just anybody diseases or illnesses; he gives them to people that need the challenges in life and will pull through it. It just feels so great afterwards knowing that you did such a good thing for yourself and that you pulled through. So I think that's what he would tell her. [He'd tell her] that it's not to hurt her in any way or make her sad about being sick or ill but that he gave it to her because he knew that she can pull through.

Prior to giving her interpretation of the poem, Amy revealed to me that her mother helped her understand god's purpose in giving her cystic fibrosis and explained that god gave it to her because god knew she would be able to get through it. This religiously-based explanation provided by her mother not only helped to explain the purpose in illness but it also helped nurture a spirit of overcoming, of having the strength to persevere in times of suffering.

For the spiritually committed person, struggle with the challenges of CF can become a process of working out theodicy in action. Theodicy literally means "to justify God." In theological terms, it refers to the attempt to make sense out of suffering and to resolve the question of why God would allow it. (Canda, 2001, p. 112)

Amy's reference to the source of her understanding of purpose in illness also points to the significance of her family in helping her to form beliefs about the spiritual, health, living, and the world around her. It is within the family and within Amy's religious community that shared meanings gave substance to the unknown and helped her to create a narrative that informed her sense making of living with illness along with its many challenges.

Despite Amy's formation of a spiritual stance that views illness as a challenge and a sign of her capacity to transcend its limitations, she still sometimes resisted doing what was required to maintain her health. Constant reminders from her mother to attend to her treatments along with "wake-up calls" from god and her illness summoned her back to her purpose. Within this tension, Amy's idea of a meaningful life, which entails having fun and spending quality time with friends, is juxtaposed with having a long life and realizing the goals for the future for which she has planned. This resistance symbolizes the desire for freedom, yet this freedom exacts a price. The price is realized

when the body becomes informant of things gone awry and when relationships suffer as a result of her will to choose resistance over acquiescence and adherence.

### **Nurturing a Sense of Awe and Wonder and Self as Capable and Responsible**

**Crackle (10 Years)** □ In Crackle's stories of illness, he also described how time was spent and how illness often took him away from the meaningful and enjoyable activities in life. When talking about the need for frequent reminders from his father to attend to his treatments, humor brought them together in mutual agreement about the challenges of illness with regard to time management. They shared a lighthearted banter that signified acknowledgement of the shared responsibilities and the strictness that was needed to facilitate adherence to the time-consuming treatment regime. The seriousness of the exchanges was downgraded by playfulness that revealed the bond that was forged between them through shared management of his illness. Underlying this exchange was also the expressed value of Crackle taking on some of the responsibility for managing his time and his illness. Knowing that Crackle would eventually have to manage his illness on his own, his father was attempting to instill this value, and thus prepare him for his maturing role in the management of his own health. □□

Although Crackle sometimes resented the impositions of his illness, there was a balance in his view of having CF; he was able to see how his need for treatments granted freedoms in addition to the restrictions they imposed. Treatments were viewed as advantageous, especially at bedtime when doing the treatments resulted in the bending of rules allowing Crackle to stay up later than usual. He saw this as an additional freedom that was a benefit of the usually annoying treatments. These times were not only viewed as a privilege but also as shared quality time between Crackle and his father.

Crackle talked about experiences of driving alone with his father during trips to the IWK when he and his father spent time doing "loads of stuff." He recalled one of the conversations between him and his father during one of these trips when they talked about banking. When he asked his father to remind him of what it was about, his father explained that they talked about banking, interest, and the economy and relayed his intentions to help Crackle understand what was happening in the world around him. "Hence, the child's social and relational context is of key importance to the evolution of values and ethics, paving as it does the eventual road to independence of thought, choice,

and action” (Walters, 2008, p. 278). Illness, its treatments, and the resulting time spent together afforded the opportunity to share quality time, time in which Crackle’s father was able to instill family values and impart knowledge to help Crackle grasp important concepts and make meaning in life events.

The spiritual was also recognized in the nurturing of Crackle’s sense of self. Throughout our conversations, Crackle’s father often interjected with comments of praise, extolling Crackle’s “savvy,” talents, and abilities. The praise that his father bestowed upon him was further encouragement and acknowledgement of Crackle’s self-efficacy. It seems in part at least that it was through this acknowledgement that Crackle was able to see himself as capable. This translated into a confidence that Crackle often displayed in his descriptions of himself and his abilities.

### **The Spiritual in Family Connectedness**

**Matt (13 Years)**—Family was also an important influencing factor in Matt’s life as revealed in his depiction of what spirituality meant to him. He relied on his family for support and said that he felt that he could go to his parents with worries or concerns. He also talked about his relationship with his younger brothers.

Matt: They’re pretty wild.

Interviewer: [Laughter] Are they . . . the younger ones? Yeah.

Matt: They like to wrestle with me.

Interviewer: Uh huh . . . so you’re the older brother for them . . . Now what’s that like?

Matt: Well, the ground I walk on, they worship.

Interviewer: Uh huh.

Matt: Everything I like, they have to like . . . like hockey teams and baseball teams.

Interviewer: Yeah . . . you’re their role model.

Matt: [Nods affirmative]

Matt saw himself as being an important influencing factor in his young brothers’ lives. His identity and all that he is was affirmed and even revered by them, giving him affirmation as a valued other. He also talked about his father being a role model, someone he wanted to be like, someone who was funny and a “good people person.” The meanings he gave to life were influenced a great deal by his family who gave him direction in ways of living and being in the world. With regard to illness and its impact on relationships within his family, Matt reflected upon his relationship with his sister.

Interviewer: Tell me about your sister. How do you guys get along?

Matt: Better . . . better than before I got diagnosed.  
Interviewer: Can you explain that? What you mean?  
Matt: Before we used to fight a lot, like seriously. Now we just play fight.  
Interviewer: Yeah?  
Matt: Like arguing before.  
Interviewer: What do you think that's about?  
Matt: [Deep breath—silence for a few seconds. I sensed some emotional difficulty in answering].  
Interviewer: You get along better.  
Matt: Yeah  
Interviewer: She's good to you.  
Matt: Most of the time.

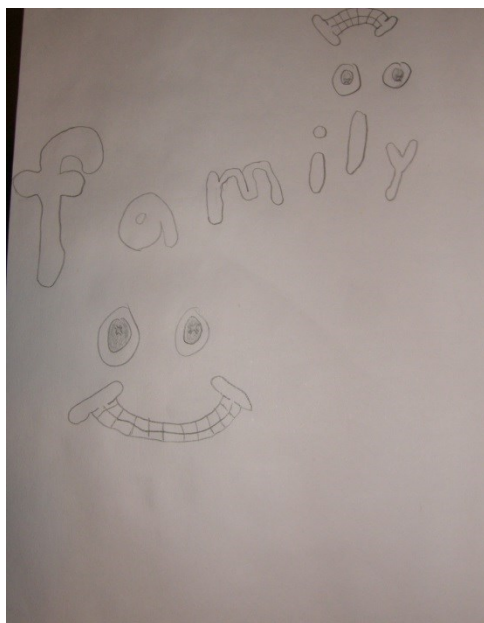
Matt did not elaborate on reasons for such a change in his relationship with his sister. Nevertheless, being diagnosed with cancer had an impact on their behavior toward each other. Matt sensed that his sister was being nicer to him and that their previous ways of being with each other had changed. A diagnosis of cancer disrupts not only the diagnosed child's sense of self, but also the relationships they hold with others. Family roles and functioning change to accommodate the ill child's needs, and there may be a sensed vulnerability of that member. Matt's diagnosis of cancer set the backdrop for a new way of life within their family, one in which their relationship seemed to be strengthened with a renewed sense of togetherness. Perhaps there was an existential fear—a fear of losing Matt that forged this family relationship closer.

Sibling relationships sometimes become closer as a result of a diagnosis of childhood cancer and have been “characterized by a spirit of community and common history, events in daily life, as well as thoughts of an existential nature, such as loyalty” (Nolbris, Enskar, & Hellstrom, 2007, p. 111). Being witness to the suffering of others in the family, healthy siblings may worry in silence that their sibling could die but may not be able to voice this (Nolbris et al., 2007; Sloper, 2000; Woodgate, 2006a). This coincides with the felt sense that illness was unspeakable, a theme that was threaded throughout Matt's stories.

Sometimes well siblings also feel the need to protect their ill sister or brother and to refrain from doing anything that might upset them or the family. These and other existential concerns such as quality of life and new ways of living within the family were common themes in siblings' narratives (Nolbris et al., 2007; Woodgate, 2006a). Families become an important source of spiritual strength in children's efforts to survive and

thrive as they live through the cancer experience. Supportive family relationships during the cancer experience are perhaps even integral to keeping the spirit alive in a family's fight against a disease that threatens to break them (Woodgate & Degner, 2003). Spiritual growth and development may depend in part on the cohesiveness of the family since social support is perhaps one of the protective factors at play in children's psychospiritual growth in times of trauma (Parry & Chesler, 2005). Living through the cancer experience, children may also re-evaluate the relationships they hold and realize a deeper appreciation for those loved ones who were supportive witnesses in their suffering. This may even become the standard by which children evaluate future relationships (Parry & Chesler, 2005), hopefully gravitating toward those that are spiritually sustaining.

**Bob (9 Years)**—Bob also talked about the importance of family in helping him to overcome the challenges of his illness. When asked to draw a picture of what helped him through the time of his diagnosis and treatment, he created the drawing below.



**Figure 9.1: How I Got Through**

Interviewer: So tell me about this one.

Bob: How I got through in the hospital.

Interviewer: Mmm hmm, family. Are these anybody?

Bob: The small face over there is Timothy [brother].

Interviewer: Timothy, mmm hmm.

Bob: And that's Dad.

Bob recalled always having someone there with him and that he was never left alone. He said that it was usually his mom who stayed overnight with him and that she would rarely leave his room unless it was to go down the hall to get his food tray. He relied on his mother a great deal. His mother was the one who provided comfort and nourishment while he was confined to hospital. When his father and brother came to visit, he experienced a sense of family togetherness. He was also afforded some relief from the monotony of his situational confinement. This time spent with family was meaningful and gave Bob a sensed feeling of being important, valued, and loved. This knowledge of his family being there for him is what helped him get through. It gave him a reprieve from the relentless impositions of his treatment and a renewed strength to persevere.

**Tony (10 Years)** □ Tony's descriptions of his experiences of family exemplify a sense of connectedness. As a child who had a difficult beginning in life, he was fostered by a new family who attended to his physical, emotional, and spiritual needs. They fed him and nurtured him, and he was accepting of their strictness because this ensured that he received his treatments that would keep him alive and well. He needed this family and they responded to his call. In the following conversation with Tony's father, he described what it was like adopting a child who required time-consuming daily medical treatments to ensure his survival and well-being.

Dad: It was unreal. At first I wasn't sure about taking on a child with CF. So I got a feel for it and I got to know more and more about it so that didn't bother me anymore. That's the way it is . . . So I don't mind at all now, you know. So I do his therapy with him and take care of his medications, and this is how we live now, you know so... Because he said, what was it [that] he said? 'Dad, by Christmas my CF's going to be gone.' I wish that was true, hey bud [to Tony].

Interviewer: But you adapt to it.

Dad: Oh yeah, you can adapt to anything, but you have to have the heart and soul to do it too.

Originating in Old English, soul is the “emotional and spiritual part of a person, [their] animate existence,” while heart denotes “heart; breast, soul, spirit, will, desire; courage; mind, [and] intellect” (Harper, 2001-2013). Having the heart and soul to take in a child with serious health problems and willingly sacrifice their family's way of life for that child's well-being is a profound act of spirit that was not lost on Tony. Tony's father then said that it was Tony who had asked to be adopted. Tony knew that he needed them and

their loving care in order to maintain his health and to grow up well. Tony realized this; and even believed that the care he received from them would cure him of his CF. This belief in his parents' ability to cure him of his illness is similar to his revelations about what god does for people. "He keeps people alive, healthy, and safe."

When asked about what being adopted meant to him, Tony said that it meant, "having a better life" because he was able to be healthy. He said he has "good parents" and described how his mother cooks for him and how his father does his physiotherapy treatments. Although he said they were strict and made him do his treatments, his father confirmed that Tony did not complain or resist. He viewed his parents' enforcing of the rules around his treatment schedule as a symbol of their love for him and their concern for his well-being. When asked about a special time he spent with his parents, Tony said, "Every day is a special day around here because I'm with my family."

**Jake (11 Years)** □ Within Jake's story of immense suffering, there was a profound sense of connection to his mother. Given Jake's lack of reported social supports, his mother was his primary source of comfort. This all-important relationship became the means by which Jake transcended illness in the acceptance of his death.

Interviewer: So who do you go to and who helps you when you're feeling this way?

Jake: Hmm?

Interviewer: Who helps you? Who brings you comfort?

Jake: I guess mom, the closest.

Interviewer: What kind of things do you go to your mom for?

Jake: Um, I don't really go to her she just comes to me.

Interviewer: So if you had concerns or worries, who would you go to?

Jake: I don't really go to people.

When asked whom he would go to with concerns, Jake said he did not really go to people, indicating either the unavailability or inaccessibility of others or an unwillingness to talk to others about his feelings. When asked what he does with these concerns, Jake became frustrated with the questioning and declined to answer. Although his refusal to articulate his thoughts and feelings may have stemmed from misunderstanding of the question, other questions about coping were similarly rebuffed. For example, when asked again later how he dealt with the pain and all the horrible things about his illness, he again had difficulty explaining what helped get him through.

What was obvious in Jake's story, however, was his strong attachment to his mother and the integral role she played in helping him get through the horrible agony of his illness. Jake's mother was "the important one," the one who loved him unconditionally and who could anticipate his needs and attend to them in a way that made him feel cherished and valued within a place of belonging. There was a sense of "at oneness" between Jake and his mother that enabled them to see the other and be with one another as witnesses to each other's suffering.

The closeness Jake felt toward his mother can be further corroborated in a telephone conversation I shared with her months later when Jake was dying. She told me that Jake was not talking to anyone other than her and that she spent most of her time with him attending to his needs. His siblings had also returned home, and according to Jake's mom, this further increased the need for her around the house. In his uncertainty, fear, and anger there remained an enduring connection with his mother that seemed to be one of the few sources of comfort in the midst of his suffering.

During our conversation, Jake's mother relayed to me that Jake spoke of his concern for her present and future well-being. She said that he recognized how the responsibilities of care giving were taking a toll on her, and although he needed his mother to take care of him, he worried for her health. Children that survive the cancer experience sometimes harbor a lot of guilt over having put their family through such a harrowing illness experience and hold the most guilt with regard to the acknowledged suffering of their mothers. Despite this, these survivors claim that they became much closer with their mothers because of this shared experience (Cantrell & Conte, 2009).

In acknowledging his mother's suffering and impending loss, Jake's mother relayed his wish for her to look after herself and to find things to fill her time after he was gone. Dying children often express their worry for loved ones, especially concerning how they will cope after their deaths (Foster et al., 2012). Jake worried for his mother perhaps because he knew that her devotion to him was all consuming and exhausting and that his death would leave a gaping hole in her life. Jake's recognition of his mother's needs and his wish for her future well-being is an insightful and loving projection that mirrors the feelings his mother had for him. As he lay dying, reflecting on what he saw, he was able to transcend his own suffering to recognize and attend to that of his mother.



In seeing her suffering, he reached out to her in caring with a message he hoped would sustain her through her life without him.

Even in the face of death, families of children with cancer maintained that it was important to “keep spirits up.” After the loss of a child, families also expressed the importance of keeping the dead child’s spirit alive as a means of facilitating family coping and sustaining the spiritual health of its members. Although support from within the family unit was the most significant impetus for keeping the spirit alive, spiritual strength was also drawn from supportive communities of others to which they belonged (Woodgate & Degner, 2003). Despite varying belief systems among some adults with CF, there was a shared sense that spiritual beliefs, experiences, and community supports helped them to transcend the challenges of their illness. This seemed to lead to transformation of the illness experience into one of spiritual growth and healing even in the face of death (Canda, 2001). For Jake, meaning making and the spiritual seemed to be navigated through the connection and conversations with his mother during the last days of his life. Perhaps facing the certainty of death prompted dialogue in which Jake was able to express his beliefs in an afterlife and the promise of reuniting with loved ones.

### **Community Spirit: Giving, Receiving, and Belonging**

In an attempt to understanding the meaning of spirituality to children, a few were asked what “community spirit” meant to them. The answers provided reveal a sense of togetherness, people working together, others being there for them, and the feeling that it is a nice place to be. Experiences of the spiritual were sometimes realized within a community of others in which the children felt a sense of others coming together for them. In other stories, children revealed ways in which they were there for others. In the following section, the children share stories in which they experienced a felt sense of community, a sense of others being there in spirit and ways in which they experienced the giving of self to others.

#### **Quadeher (13 Years)**

While Quadeher talked about the importance of family in his life, he said that he even considered some friends to be brothers and sisters. As an only child, Quadeher found belonging in a community in which he adopted others as part of his family. When

asked to think about what was spiritual in his life, Quadeher drew a picture depicting spent time with his “brothers” at bible camp.



**Figure 9.2: Quadeher and His “Brothers”**

Coming from a small community, Quadeher experienced a sense of belonging that went beyond that of traditional community connections. Friends who were considered part of his family were important sources of support for Quadeher. Knowing that they were there for him helped him to get through his initial diagnosis and treatments when he was so far from home for so long. He stayed connected with these friends by phone, computer, and by them coming for weekend visits.

This felt sense of communion with others was realized in not only the visits, phone calls, and messages from his friends, but also in the acts of the whole community in which Quadeher lived. Quadeher described his delight in the kindness of others in his class when they pooled their money to buy him a new DS video game player. After hearing that Quadeher’s DS got broken, and knowing the financial burden their family was facing, his class gave a gift that communicated caring and concern and that they were there for him. This, in turn, lifted Quadeher’s spirits, providing him with a means of spending time that brought him some joy in the midst of his isolation and suffering.

Quadeher described community spirit as when people “stick together,” denoting a sense of coherence or “at oneness.” In addition to experiencing the outpouring of caring and support from his classmates, Quadeher also described the experience of his homecoming after being away for eight months during his initial diagnosis and treatment. He remembered getting home and seeing teachers, janitors, and students from every grade there to greet him. They were happy to see him home and they rallied together in

an act of community spirit in which they celebrated his return to the home where he belonged.

Prior to our final meeting, I sent Quadeher a list of questions asking him to think about experiences of the spiritual in his life. In response to these questions, Quadeher described an experience of speaking in front of a group of peers at bible camp motivated by an invitation from the pastor. During this speech, Quadeher shared the story of his experience of having cancer and the challenges he faced. Moved by his stories, two female peers wrote letters of prayer and encouragement to Quadeher. The letters spoke of their admiration for his courage and contained prayers and messages of caring and hope. “Prayer, as a means of conveying divine power from one to another is a unique form of social support not found in non-spiritual domains of caring” (Crawford et al., 2006, p. 357). For Quadeher, these letters spoke of the spiritual. In receiving these messages of caring and hope, he was infused with a knowing that others were there for him, wishing him well, and praying for his well-being.

These experiences of giving of self through stories and receiving prayers and messages of care and hope encouraged Quadeher to continue to tell his story. Prior to our third meeting, I received an email from Quadeher’s mother. In it, she described a story of how Quadeher shared of himself with others.

Mom: Our church was cancelled this morning, as the pastor is away. We usually stop in to the nursing home to visit with Quadeher's great-Grammie on our way home. This afternoon, we went up just the same. While we were there, one of the staff came in to announce the afternoon minister didn't show up. They were looking for a speaker, and when they found one, they would start the church service. When she eyed Quadeher, she came over and asked if he would speak about his experiences this past year, and how God has helped him through. He agreed, quite quickly! I was shocked, as Quadeher has NEVER been a public speaker, always quite shy and reserved. He spoke earlier at the Relay for Life Survivor Supper, so I knew he could do it, but honestly didn't expect he would go so willingly. Yeah! The nursing home had its speaker for today's service! Quadeher spoke about going to the IWK, and how he met special friends Susan and Mitchell. He spoke about how rough it was being away for eight months, and how good it was to see all his friends at the homecoming. He also talked about how good it was to have so many people praying for him, especially all his friends at Youth Group, and in his Sunday school class. It was good to have so many youth [in our

community] AND friends away praying for him, and now he's glad to be back home, feeling better all the time.

During our conversations, Quadeher also spoke about the special friendships he made, how he missed being with his friends from home, and how good it felt to be welcomed home by a community of people who were there for him. Knowing that others were praying for him and sending him well wishes provided him with a connection to others that sustained him and lifted him, giving him the strength to overcome the challenges of being ill and away from home. Within Quadeher's message were elements of hope and inspiration that spoke of the spiritual as a driving force behind his ability to persevere in illness.

Communal spiritual well-being or "having strong interpersonal relationships based on friendship and/or love" (Rowold, 2011, p. 961) may also be a source of children's happiness (Holder & Coleman, 2009; Holder et al., 2010; Rowold, 2011). Referring back to the earlier discussion, long-term happiness and thriving seem to stem from a sensing of the spiritual (Eaude, 2009; Holder et al., 2010) and it is the personal (meaning and value in life) and the communal (the quality and depth of interpersonal relationships) that seem to contribute most to children's happiness. It is within these important relationships shared with family members and close others that children are able to find a sense of identity, meaning, and purpose in their existence, especially in the face of adversity (de Souza, 2009).

### **Bob (9 Years)**

When Bob was asked about the meaning of community spirit, he explained that it was "working together" and "finding solutions." Although he was unable to articulate any specific experiences of community spirit, he later talked about his involvement in an event that embodied the spirit of coming together to help others. He described his experience of being involved in a yearly fundraiser with his father and brother called "Hair for Hero's" in support of the Daniel McLellan Memorial Fund. Each year they would work together as a family with other like-minded community members to raise money and participate in the event by shaving their heads. This event symbolized the spirit of giving. It showed how Bob's family came together each year with a community of caring others to raise money for families who also have children with cancer. Within this coming together to find solutions, Bob is taught about the value of giving and spends

meaningful time with family and community in which he witnesses community spirit and participates in giving of himself to this meaningful cause.

Bob also talked about other experiences of community spirit in which caring others were there for him. He talked about being in the hospital and receiving visits from members of his church community along with gifts and messages of inspiration. As he talked about these visits and gifts, he jumped up with excitement, ran to his room, and returned with something to show me. In his hands was a stuffed frog. With a wide, expectant smile, he pressed the frog's stomach and it began to sing "What a Wonderful World" by Louis Armstrong. This was a gift from someone from his church, who gave him presents for doing well in the hospital and for taking medicines he did not want to take. The message to Bob was that despite the difficult situation he found himself in, there was still a world beyond him and around him full of wonder, beauty, and love. It was a message of inspiration and encouragement meant to lift him up and help him continue in his struggles to overcome the challenges of his illness.

### **Amy (13 Years)**

Amy also had a large community of caring people that she could draw upon in times of need. Amy was also quite resourceful in seeking out people in her life who supported and nurtured her. In addition to the friends who stood up for her and helped her to stay well by reminding her of her need to attend to her treatments while at school, there were supportive teachers who would be there for her as well. She talked of the resource teacher in particular who helped her with her treatments and who would listen and support her when she was hurt and frustrated by the bullying she endured.

In addition to these resources, Amy also belonged to a religious community that came together to support her in times of need. Amy described what it felt like to have other people praying for her when she was sick in the hospital.

Interviewer: What feeling does that give you when people are praying for you?

Amy: Well it's a good feeling because then you know that there are people that care about you even when you have a bad day and you think that they're not. There are people who care about you and just, they prove it by helping you and stuff . . . so, they pray for you. It's a good feeling and it makes you have a feeling that I'm going to do this, I'm going to pull through. Everyone else thinks I am and I'll prove it that I will. And

it's more of a thing like, this is nothing; I'm going do it. I'm going get out of this hospital and go home and see all my friends, so it's a good feeling.

In these prayers, there was a felt sense of caring that gave Amy the strength to persevere. This unseen force or energy was inspirational and encouraged Amy to keep going despite having a bad day. There was a sense that others not only cared for her, but they believed in her as well, giving Amy a renewed belief in self as capable of overcoming. Prayer is a powerful support that can be healing, helping people to overcome exacerbations of illness and transcend feelings of doubt and despair (Canda, 2001).

Amy also described how others' stories and experiences provided inspiration to her and how they helped her to make meaning in her own experiences with illness. Amy talked about Terry Fox. She marvelled at how he did not give up, despite being tired. She also described how her grandfather overcame a serious illness that left him debilitated for one and a half years. Being witness to others' stories and experiences, she was able to believe in herself as capable of overcoming her illness. She was inspired by others' stories of triumph and resilience, renewing her own spirit to fight her disease in times of struggle.

In her recognition of the inspiration provided by others, Amy also gave of herself in ways that demonstrated her ability to see beyond herself. In the case of her grandfather, Amy not only drew inspiration from him, but also provided inspiration, encouraging him to continue fighting when he felt he could not go on. She prayed for him and remained with him, helping him to walk and do things he could not do for himself. By giving of herself, she helped him to overcome the challenges that he faced.

Amy's strength of spirit revealed itself not only in her belief in herself but also in her belief in others and in her compassion and sharing of self through prayer and in physically caring for another. Whenever she felt ready to give up, she just thought of others who have overcome difficult times and realized that if they can do it, she can as well. This inspiration was like an intake of fresh air, a breath of life that Amy called upon in times of need. Likewise, Amy inspired others when support and encouragement were called for.

### **Tony (10 Years)**

Like Amy and Quadeher, Tony was also surrounded by a religious community who gave him a place of belonging. Being able to take the bread and the wine was a rite

of passage that symbolized his spiritual connection with the transcendent and a community of caring others. Rites of passage such as these are traditions that facilitate a sense of spiritual consciousness and a sense of being part of something beyond the self. In turn, he was able to demonstrate a gift of self through his willingness to give back to his church community through altar service. He felt a sense of pride in this service as it was a concrete and visible display of his contribution to his religious community. It symbolized the importance of his maturing role in this community and the value of his membership in a place of belonging, which in turn may contribute to his resilience (Fernando & Ferrari, 2011).

Tony expressed wishes for a better world that spoke of his ability to see beyond himself to the global community of which he belonged. When asked what he would pray to god for, he said that he would pray for world peace. He wished that there would be no more earthquakes, sinkholes, and planes crashing. As he was inundated with messages of destruction and devastation around the world, as it came to him in dour news reports, he was affected by the suffering of others. His wishes for a better world spoke to his compassion for others and his recognition of self as belonging to a global community.

### **Jake (11 Years)**

Jake also belonged to a religious community. However, when prompted, he declined to answer many of the questions about his religion and church. I wonder if perhaps he was angry with god and maybe did not see this community as a place of belonging for him. Despite his reported lack of social supports however, Jake recognized that he had many friends at his school. He mentioned his knowledge of these friends through an assembly arranged at his school in which everyone gathered in the gym and showed support for him in acknowledging his illness and what he was going through. This acknowledgement and show of support led to a feeling of friendship for Jake despite his not knowing the names of over three quarters of the people there. He was aware that others cared about him and were reaching out to him in their wishes for him to be well. It was a showing of community spirit in a message of caring from afar.

Despite his profound suffering, Jake was able to see beyond himself to recognize the needs of his mother. He was also able to see beyond himself in his wish to contribute to the greater world for the betterment of others. During my last conversation with Jake's

mother, she revealed that he had a wish to write a book that told of his experiences and his desire to make a difference in the world. He wanted to share his story in the hope of inspiring others. He also talked about how he wished he could have become a doctor so that he could help find a cure for cancer. This altruistic desire to help others by entering the healthcare field was common among childhood cancer survivors, who through their experiences of suffering had a profound sense of wanting to make a difference and to relieve the suffering of others (Parry & Chesler, 2005).

As he lay dying, Jake expressed wishes for others and a desire to help others who suffer as he had. His wish to leave a legacy through his writing also spoke of his yearning for continuity and remembrance through the sharing of his experiences and his desire to express the meaning of his life. This desire for continuity and remembrance through leaving a legacy that conveys the meaning in one's life was also expressed by other children who were dying (Foster et al., 2012).

### **Summary of Findings**

All of the children in this study, regardless of illness type or symptom severity, expressed that illness had disrupted their lives in profound ways. Living in a body that betrayed their intentions not only led to limitations and visible differences but also resulted in missed time and lost opportunities to be a child, threatening their sense of identity, place, and purpose. At times illness created tensions with parents and contributed to social isolation and perhaps even spiritual suffering. At the same time, however, a strengthening of relationships within the family and community revealed the spiritual at play within these connections. Playing and spending quality time with family and friends seemed to imbue their lives with meaning. Play was also a vehicle for expression of the spiritual and for managing and making sense of illness. While connections to important others were a source of support and identity formation, they also provided a touchstone that contributed to a sense of coherence in terms of meaningfulness in life and manageability of illness.



## **Chapter 10: Conclusion**

### **Weaving Understandings into a Meaningful Whole**

This research centered on understanding spirituality as lived by children in the context of two serious illnesses. It highlighted how the children grappled with and made sense of a life beset by illness, and how the spiritual was implicated. The lived experience of the spiritual is often unarticulated and hidden, making exploration of the topic challenging. Many who have attempted to understand this phenomenon among both ill and healthy children have admitted to this difficulty, yet they persist, claiming that it is a topic too important to ignore.

While there are many ways of approaching this type of inquiry, I chose hermeneutic phenomenology because it enables the exploration of lived experience in an attempt to understand what is hidden in the “everydayness” of life. Hermeneutic findings provide deeper understandings of lived experiences. They are not generalizable, nor do they provide prescriptive guidelines for applying findings in practice. Instead, hermeneutic inquiry presents its findings as an address in which the reader is prompted to see how the findings bring to awareness what is already known pre-reflectively but is perhaps forgotten. It is an address in which “the very detail of the individual brings us closer to significant aspects of a shared humanity” (Smith, 2004, p. 43).

I begin this chapter with a discussion of the challenges and limitations inherent in the study of spirituality among children. I will follow with a brief summary of the findings and discuss their relevance to child health as well as how they add to previous understandings. Finally, I will discuss the implications of these findings for practice and for integrating policy, research, and education in ways that may lead to more holistic child healthcare.

### **The Limits of Language**

One of the major challenges of exploring the spiritual among children was the issue of language. The spiritual is often difficult to describe for adults, let alone children. Choosing study participants aged 9 to 14 years was purposeful, related to the assumption that children of this age might be more able than younger children to reflect on the spiritual and find language adequate to express their experiences. Excluding older children reduced the possibility that a greater capacity for linguistic expression would

overshadow the experiences of younger children. Although this may limit understandings of the lived experience of the spiritual for older or younger children, some findings may still have relevance regardless of age differences. Analysis of approaches used may also offer possibilities for adaptations that are more amenable to having spiritual conversations with other age groups in the context of future research and practice.

Although the children in this study seemed capable of grasping abstract concepts, some still had difficulty expressing these in language. For the less talkative children, finding the language to describe lived experiences of the spiritual was especially challenging. Although the interview guide (See Appendix F) provided direction for beginning a conversation about the spiritual with children, the interview questions do not provide a set way for opening dialogue about the topic.

While broad relational categories offered direction for the inquiry that prevented theoretical and conceptual framing of the topic, the specific questions asked during the interviews were not read verbatim. Rather, questions were more responsive to what the children were actually saying—the conversations were co-created. This conversational style was less formal and focused on the topic and whatever was meaningful to the children. When children offered clues to deeper meaning, these issues were pursued with subsequent open-ended questions and prompts that encouraged further elaboration.

Some children had difficulty articulating responses to some of the questions, while others had no difficulty. This did not seem to be related to age however. For example, Bob (9-years-old) and Matt (13-years-old) both seemed to understand when asked if they looked at life differently since having cancer. Matt answered affirmatively as he hung his head in silence, unable to speak. Bob referred to bedtime rituals and symbols of meaning that related to transcendent connections that seemed to provide a sense of comfort and security. Both children had difficulty articulating their responses in words, yet both had something important to convey. Understanding in this situation demanded an openness to listening for the spiritual (Gersch et al., 2008); this included an attentiveness to the meanings children attached to experiences in their lives. Such listening requires sensitivity to the nuances and underlying feelings in children's expressions and an attunement to experiences that animate or deflate (Nye, 2009).

At times during the conversations, I had to reword questions to harmonize with the language of the child. For example, when obtaining consent and assent, children were asked if they had heard of the word spirituality. Most had not. Among those who had, many had difficulty finding words to describe it. This required rewording of questions such as asking if they had heard of the word religion or church and what this meant to them. I also attempted to understand the spiritual in their lives by using the word spirit in other contexts such as “community spirit,” and rephrased questions when I thought a child might have misunderstood.

Unfortunately, these techniques did not always result in further dialogue. For the less verbose children, providing specific open-ended questions about spiritual experience to contemplate between interviews was a strategy that seemed to yield more elaborate expressions than those elicited during interviews. Children’s reticence during interviews may have been due to a reluctance to share such private inner thoughts with a stranger. Perhaps the children’s lack of expression was due to difficulty finding language to discuss something about which they had not given a lot of thought. Giving children the opportunity to contemplate questions seemed to allow the time needed to bring experience to expression. Because this technique seemed useful in overcoming limitations of language during face-to-face interviews, it may also be also be a strategy for exploring the spiritual with young people in practice and future research.

Using art as a means of expression was another way of overcoming the limits of oral language. Art is a means of communicating meanings to others (Hess, 2003; Merleau-Ponty, 1962/2002; van Manen, 2002). Art enables a mining of deeper expression of lived meanings, often saying more than words can. A poignant example of this was Jake’s use of art in his embodied expression of meanings in illness. Through art, he conveyed anger, an inner turmoil, and suffering—a suffering that was related to living with the uncertainty of illness. The pencils and paint became the medium for release, enabling Jake to convey something important. The word “good” followed by the letter “x” repeated down the page and the harsh scribbling and anger about not getting it right, were signs of what was happening to him. Only a few words were spoken, yet so much more was said. Art, in this case, brought forth his experience.

Art was also a helpful tool for Matt for expressing meanings of spirituality. At first, he had no words to describe it. Through art however, some words were found. The spiritual took shape in form of a heart, and words flowed from this, lending richness to his messages of meaning. Spirituality was “the way of life,” “what life is to you,” “friends,” “family,” and “how happy you are.” The creation of art became an occasion for mining the depths for the spiritual and for finding expression—in shapes and in words, revealing meaning that could be shared.

Crackle, Bob, and Quadeher also used art to express meanings. However, using only one method of artistic expression may have been limiting. Although drawing was the main tool used, some of the children (the two females) did not feel comfortable expressing themselves in this way. Offering alternative modes of artistic expression such as poetry or collage was a way of drawing on the preferred interests of the children. Perhaps these options were still limiting. Another approach might be to explore the passions and artistic interests of children upon meeting them, using these as avenues for engagement in exploration of deeper thoughts and experiences of the spiritual. For example, story, play, and artistic expression may be helpful in augmenting dialogue with younger children who might not have the language to express the spiritual.

### **Limitations of the Findings**

This study focused exclusively on children with cystic fibrosis and cancer. Children with these illnesses were chosen because of the life-threatening and life-limiting nature of these illnesses. “The extent to which a chronic illness will be a likely cause of death and the degree to which it can shorten one’s life span is a critical, distinguishing feature with profound psychosocial impact” (Rolland, 1984, p. 250). The typologies of cystic fibrosis and cancer share similarities in outcome in that both illnesses engender a sense of existential threat (Rolland, 1984) that tends to evoke questions of a spiritual nature. Although the findings may not provide understandings useful in all childhood illness circumstances, they may provide insights into other childhood illnesses that share a similar typology.

Other considerations in contemplating the findings of this study were that all of the children were Caucasian and lived within a similar cultural context. Of the six children who reported affiliation with a religious community, all were Christian, whereas

the remaining two children reported no affiliation with religion. While findings provide rich understandings of the lived experience of the spiritual for these children, nothing can be said about children in other contexts; some may consider that a limitation of the study.

On the other hand, a hermeneutic phenomenological study is not so much concerned with the experiences of *these* children—as important as they might be—but is more concerned with what their experiences have to say about the topic—that is, spirituality in the context of childhood illness. The interest in this study was how the meanings of illness and the spiritual were brought to expression in a way that enables meaning to be shared with others. One is less concerned about generalizing about children in this context or that, as hermeneutics does not set out to do that. Thus, the heterogeneity or homogeneity of the participants is not as relevant a question as it might be with another research approach.

Here I was concerned about what children had to say about the topic, rather than what I might say about children in these illness groups collectively. Related to this is the fact that the experience of an individual child is just as important and has just as much to say about the topic, as does a shared experience among several children. To rely on the frequency of occurrences of a phenomenon to validate its veracity ignores the truth-value in the “fecundity” of the individual case. Interpretive research “suggests that these striking incidents make a claim on us and open up and reveal something to us about our lives together” (Jardine, 1992, p. 55).

### **What I Learned About the Limits and Possibilities of Interpretation**

A quantitative researcher once asked me if this study was science, and I answered that it was. Science is, in a simple definition, “a systematically organized body of knowledge on a particular subject” (Oxford University Press, 2013). My research is not bound up with numerical results, but with language, and that makes my work open to the very questioning that it sought to address in the language of the children. In the identification and working through the biases or prejudices at work in this study, this definition of science was certainly realized. At the very least, a consistent engagement with the research from various disciplinary perspectives now adds to previous understandings by situating the data within that wider “systematically organized body of knowledge,” or context of meaning.

My approach is moreover grounded in the questions and conditions of ancient and modern philosophy that make human understanding possible. The ancients, and subsequently Heidegger and Gadamer, argued that understanding, the ancient *scientia*, relies on bias or prejudice. What is handed down through tradition is a starting point for all understanding. Our pre-conditioned understandings or biases are operative in any scientific inquiry, including the quantitative studies that seek to eliminate confusion and doubt.

In any research endeavor, there is concerted effort to eliminate any bias that may diminish the truth-value of the study findings. Understanding anything at all, however, requires interpretation that draws on intuitive faculties—ones that can be unwittingly influenced, leading to systematic error. This applies to both the scientist and the reader of scientific work (Kahneman, 2011). Because hermeneutic studies such as this one rely on the situated understandings of the researcher, bias or prejudice are implicated and must be addressed.

In his New York Times bestseller *Thinking, Fast and Slow*, Kahneman (2011) provides strategies for overcoming bias inherent in intuitive reasoning that can lead to misunderstanding. Our intuitive faculties, or what Kahneman refers to as “system 1,” connect events and understandings from memory, along with associated emotions. Patterns of similarity and coherence are quickly established based on what is known. This mode of thinking drives our daily pre-reflective actions and decisions and usually serves us well. It is also a mode of thinking that, when left unchecked, can lead to misunderstandings and poor decisions. “System 2,” the term Kahneman uses for more deliberate and analytic thinking, is engaged when words or events trigger a sense of dissonance or unfamiliarity based on what is known. This slow mode of thinking is also engaged when verifying the familiar to avoid the pitfalls inherent in the reliance on immediate intuitive coherence.

Deliberate and analytic thought is actively initiated in the reflexive process characteristic of the hermeneutic circle. A slower mode of thinking, the kind that arises in the hermeneutic approach, encourages a slow and methodical questioning of intuitive assertions by considering possible alternatives through inter-textual dialogue. It is not enough to take a statement as complete in itself. One must consider the context, the

thread of the conversational narrative, earlier and later assertions, along with the problem of language with its density and often-confusing nature. In addition, the interpreter is constantly asking herself how an interpretation is arrived at. If language is an exchange, the interpreter must be willing as well to fill in gaps the way we do in a normal conversation, not to overwrite what we hear, but to move closer to meaning.

Thus, there are situations, however, when intuition enjoys a high level of accuracy, even in the face of the above-mentioned dangers. Prolonged exposure and practice in circumstances that are “sufficiently regular to be predictable” (Kahneman, 2011, p. 240)—such as pediatric nursing—give credence to an expert interpretation or reading of similar situations. Having said this, I also know the limits of understanding and admit to the possibility of over-interpretation in some cases. For example, my interpretation of illness as “a well-worn coat” provoked a sense of dissonance for one of my readers. Consequently, I was asked to remove it because it was considered an example of over-interpretation. After careful consideration, I decided to leave it in, and I will now explain my reasons for doing so.

The “well-worn coat” is a metaphor for illness. It signifies a child’s ability to step outside of illness—to put it away for a time. It also relates to a child’s feelings toward illness as an encumbrance and a visible difference that leads to separation from peers. Appearances were important to this particular teenaged girl. To wear a coat in public—a coat that she hated—would have been quite embarrassing. The coat also represents a cloak that covers and hides what is beneath it, relating back to the child’s preference for hiding illness through silence. I have tried to enter into the emotional life and language of my interlocutor. Certainly there are places where I may have over-interpreted in my reporting and reading of the interviews, and I will emphasize with a quote from the first chapter that “[I]t would be sad indeed if fear of ‘overinterpretation’ should lead us to repress the state of wonder at the play of text and interpretation” (Eco, 1992, p. 123).

In cases where one suspects over-interpretation, it would be fruitful to appeal to the reader’s sense of the text as a whole—its internal consistency and coherence (Eco, 1992). In other words, it is how a given interpretation fits within the greater context of meaning and with the intention of the text as a whole. Because the text was produced for a community of readers, specifically those interested in spiritual care of children, there is

a humane familiarity with the plight of the participants as well as with the topic of inquiry. One's affiliation with the topic and with the tradition that informs it is what enables this understanding to take place.

This does not mean, however, that any given interpretation by the author is the only interpretation. From reading the entire work, a fresh reader may also discover additional or alternate interpretations that are fertile with meaning that go beyond the initial intention of the text. In one respect, the text is informative in helping the reader to see something differently—specifically the spirituality of ill children. The text is also intended to be generative in that it serves as a jumping off point from which a reader can make her own connections with other similar situations and with her own experiences and understandings of the phenomenon.

Although textual consistency and coherence is one way of evaluating the veracity of the findings, this is only a derivative of the truth that can be found in the work. Truth, according to Gadamer (1975/2004), arrives as an event rather than as a confirmation of veracity based on a predetermined set of criteria. Realization of truth is what happens to the reader while engaging with the text. Truth arrives unbidden and is grasped immediately as something significant—a realization of meaning that is shared. This event leaves the reader changed, unable to return to previous understandings of the phenomenon, leading to revisions in the way one lives out these new understandings in practice. “Understanding always involves something like applying the text to be understood to the interpreter's present situation,” (Gadamer, p. 307). In this sense, hermeneutics is a practical philosophy. It derives its problems from practice and relates its findings back to real-world situations.

Hermeneutic findings are never final or complete. Instead, they provide an opening, into which readers enter, replete with their own horizons of understanding that provide the conditions for experiencing the truth of the work. One's horizon is informed by history, tradition, and language and is “the range of vision that includes everything that can be seen from a particular vantage point” (Gadamer, 1975/2004, p.302). Our horizons of vision are continually in the process of being formed as a world of difference comes to meet us and as understandings are tested in light of the past and the traditions



that informed them. This being in relation with a text requires openness and a willingness to risk one's present point of view and one's trust in what one believes to be the case.

### **What I Learned about Spirituality in Childhood Illness**

The findings of this study help us to understand how ill children draw on the spiritual in an effort to find meaning and purpose in illness and in life. Findings also show a sense of struggle and, in some instances, silence in which children may have difficulty expressing or finding meaning in their experiences of illness. How children make sense of illness—the meaning that they draw—reveals the tone and texture of this struggle. Meanings reveal that which speaks to us from the depths of despair and from the lofty heights of victory. Meanings color our view of life, be it grey and cloudy or bright with colorful possibilities.

Understanding the spiritual as lived by ill children began with attention to what was revealed in participants' stories and in how they talked about their lives. It continued as I engaged with the text in relation to what I understood about spirituality from the literature, from history, from tradition, from others, and from experiences of life. The findings were integrated within a larger discussion showing how they related to previous understandings of spirituality and illness, including those from previous research.

Given the multitude of potential understandings, an alternative reading of the spiritual is always possible. It is even conceivable that some might not see the spiritual at all, for it is not an object. Rather, the spiritual is what is interpreted or read in the world and here, in children's stories. As I engaged with the children and with the resulting data, the spiritual was read in the children's will to fight—in the fight for control and freedom from restrictions of illness and in the fight for life itself. Mirrored in play, children seemed to find ways to become one with this fight, feeling the energy as it flowed through them, renewing their strength and tenacity to endure. The spiritual was also realized in the prayers, symbols, and rituals that connected the children to a transcendent source of strength, comfort, and protection or to a felt sense of love and belonging. I saw it in their service to others and their community and in the connectedness to others among whom they felt affirmed and found a home or comforting place to dwell.

I recognized the spiritual in the children's expressions through art and imagination—and in their awe and wondering. I also saw it in their hope and optimism

and in their sense of self as continuous beyond the physical and the earthly. While drawing from spiritual and secular frameworks of meaning some children contemplated answers to some of the big questions of life while others may have lived these questions in silence. It was often existential meaning, fear, or suffering that seemed to underlie both the searching and the silence. All of the children expressed concern for their lives or at least longed for lives and bodies that were free of the limitations of illness. As they lived their illnesses, they seemed to struggle to find a balance between enduring treatments for the sake of their very existence and engaging in activities that gave meaning and quality to their lives.

As I listened to the children's stories, the spiritual was heard in the voices of passion, ones that spoke of "enduring suffering" or "strong emotion [or] desire," and in deeds of compassion that signified a coming "together" in "suffering" (Harper, 2001-2013). It was felt in the tears and outbursts of anger and in the fear and brokenness bereft of meaning. The spiritual was also realized in the stories that animated and inspired and in the tales of triumph and transcendence.

### **What These Findings Add to Previous Understandings**

This is the first hermeneutic study that I am aware of that explored the lived experience of the spiritual among ill children. The findings of this study add to previous research by providing more nuanced understandings of the spiritual as lived. They add to knowledge of childhood spirituality in that they expand understandings of the spiritual among ill children who live with existential threat and uncertainty.

The findings of this study dovetail with findings of previous studies that show that children of this age have rich spiritual lives and that the spiritual can offer solace, strength, and guidance in times of crisis or distress. For one child (Amy) the spiritual was implicated in the process of finding meaning and purpose in illness. For others, the spiritual prompted reflection on life and ways of living, sometimes providing guidance that related to maintenance of health. For some however, the spiritual was implicated in the context of struggle (Jake and Matt) and in an attempt to make sense of illness, loss, and death. Finding meaning in illness is more than simple coping. Meaning making in illness can lead to profound changes in identity and worldview, contributing to longer-

term thriving and resilience (Cantrell & Conte, 2009; Parry, 2003; Parry & Chesler, 2005).

Previous research revealed the challenges of language and the difficulties inherent in the study of spirituality with children. The findings of this study provide insight about how to open conversations with children about the spiritual. They describe ways of having meaningful conversations about spiritual issues that have the possibility of revealing what may be hidden in everyday experiences of illness. Although I do not offer a set of questions that could mine the breadth and depth of the spiritual, I do propose a way forward in meaningful dialogue about the spiritual with children. It also includes openness to reading the spiritual in children's lives and a practice that recognizes the importance of the spiritual in children's coping with illness.

The findings also show how the use of art and open-ended, co-created questioning about spiritual and existential issues can be useful in helping children to contemplate life and illness and in creating a narrative that can lead to a sense of coherence and wholeness. Giving children time to contemplate these questions, also gave children the opportunity to express deeper thoughts and feelings.

A deep understanding of the spiritual can only be realized through experience. To become experienced with something is to be present in its revealing—to be touched by it and to be changed as a result. It is an awareness of having been transformed by what strikes us as familiar, or perhaps foreign, that resonates with meaning in the depths of our being. In our busy lives, perhaps we forget to focus on the here and now and what comes to meet us. We may not see the spiritual because we forget to look, and perhaps in our forgetfulness, we remain silent as the spiritual remains hidden in the mundane, taken for granted aspects of life. We may also miss the spiritual in life if we are not open to it or if we choose not to read the world with a spiritual lens.

### **The Whole with Relation to Health**

Our view of the spiritual is colored by our lived understandings. Accumulating visual images, sensations, and associated emotions of primal relationships held in memory are thought to form the beginning of spiritual experience. Early in life, we come to understand ourselves as individuals, effectual, yet vulnerable, interconnected and interdependent. We learn about the world, our place within it, and ways of being and

seeing that fit within our cultural understandings. Later, language, symbol, and action become the expression of the spiritual, who we are, and what we hold dear.

If we are blind to the spiritual as it flows within the lives of ill children, we may be neglecting our ethical responsibility to heal and to nurture this aspect of life, an aspect that may be important to their well-being. To heal is to “make whole” again (Harper, 2001-2013) denoting a sense of integration of all aspects of being. Perhaps in illness there is a feeling of dis-integration that calls for a re-membering of parts. Finding existential meaning and purpose in illness and suffering is perhaps one way that children can integrate illness with self that provides a home in which to live illness and the spiritual with integrity and wholeness.

All of the children had ways of living the spiritual that contributed to wholeness and health. For Amy, finding meaning and purpose in illness and in life seemed to lead to changes in her worldview and in her attitude toward life. It kept her focused on living and her responsibility for her health and to others. She found strength in her spiritual beliefs and seemed to use them as a framework to explain the ineffable and to provide direction for ways of living her life with illness. She was also guided in the formation of her own identity in a way that nurtured a sense of self as capable and free to choose. She actively engaged with transcendent others through prayer and drew on the spiritual in her connectedness with others who affirmed her worth and belonging.

Crackle’s spirituality was expressed in his sense of awe and wonder. He seemed to be interested in what was beyond and around him, like the history of knowledge and technology, the environment, and the economy. Guidance from his father and perhaps other sources provided a space for engagement in dialogue that helped to increase his understanding of self and his place in the world. He connected to the transcendent through play and symbol and expressed great concern for the earth and views of religion that have global relevance.

While all the children revealed experiences of the spiritual and were resilient in their own ways, some exhibited a “sense of coherence.” Coherence is when something has “the quality of being logical and consistent” or “the quality of forming a unified whole” (Oxford University Press, 2013). Coherence is a sense of things sticking together

(Harper, 2001-2013) and making sense. Coherence in this context relates to making sense of illness and having a sense of the whole in relation to one's existence.

The term coherence was first introduced into the health literature by Aaron Antonovsky (1979), as an indicator of stress effects on health and well-being in which stress is detrimental to health only when it disrupts one's sense of coherence. Having a sense of coherence stems from understanding that life is comprehensible, manageable, and meaningful. It is born from a belief that things happen for a reason, that there is order to life, and that life is understandable and predictable. It is realized in the knowledge that supports and resources are available and that one has control in the situation and is capable of overcoming life's challenges. It is also nurtured by a sense that there is meaning and purpose in life and that life is worth living (Raftopoulos & Bates, 2011).

From a spiritual perspective, perhaps one's sense of coherence flows from finding and integrating a sense of meaning and purpose in stressful life events as they pertain to one's ultimate existence. This search for meaning and purpose is also tied to one's relationships with self, other, and the transcendent. For example, finding meaning in illness and suffering enables children to view a stressor as understandable and predictable. Knowing that there are others in the world [and perhaps beyond] who care for them and who will be there for them in times of need leads to a viewing of the world as a place of safety and belonging, giving children a sense of hope in knowing that they do not have to face life's challenges alone. A view of self as capable of transcending life's challenges is linked to a sense of identity and purpose and a confidence in one's strength to persevere. As discussed previously, our way of viewing self, other, and the world becomes part of the foundation of spirituality and informs the ways we respond to events, others, and to the world around us.

For some children in this study, a narrative of illness as unspeakable may have contributed further to their suffering. For those who were suffering in silence, the spiritual seemed to have gone unrecognized or unarticulated. Loneliness, alienation, and separation of self from illness and others may have been magnified. Meaning, identity, place, and purpose became lost without a coherent narrative to make sense of life. Perhaps this can also be viewed as disembodiment of spirit, a lack of wholeness, and a disconnection of self that longs for meaning, integration, and a place to call home.

Some participants' inability to talk about their suffering and the spiritual may be partially due to limitations inherent in the types of questions asked, or because of the children's inability to find suitable language to describe felt, or embodied experience. It may also have been due to possible feelings of vulnerability in disclosure within a tentative adult researcher child relationship. For some it may have been a learned way of being or perhaps the fear of bringing suffering and vulnerability to the surface. Without this narrative, perhaps meaning and purpose in illness, suffering, and life was not realized, leaving children to continue suffering with unanswerable questions. I wonder if we perpetuate this silence by assuming children do not have the capacity to contemplate such weighty questions or because we struggle with finding appropriate ways to approach such sensitive subjects. We may even remain silent in our desire to protect children from suffering. All the while, they may already be suffering, remaining silent along with us. "Illness suffering is unspeakable in many contexts, and thus, suffering conversations are absolutely necessary in clinical work" (Marshall, Bell, & Moules, 2010, p. 203).

While adolescence marks a time in development when the young may begin to grapple with questions of identity, place, and purpose and the finitude of being, this is perhaps an ideal time to engage them in reflection and dialogue. It is noteworthy that death was a topic that emerged naturally in conversations with all of the children in this study, providing an opening for talking about spiritual issues. Some believe that engaging children in conversations about life, death, and suffering is one way to guide them in finding answers to such spiritual questions (Champagne, 2008; Eade, 2003, 2009). Although there are no definitive answers to these questions, Hay and Nye (2006) suggest that instead of providing answers, adults should appeal to children's sense of awe and wonder. If given the opportunity, young people may surprise us with their insight and wisdom, opening a world of possibilities for living illness informed by the spiritual.

### **Seeing the Arcane in the Mundane**

Before beginning this exploration of the spiritual lives of ill children, I had the sense that the spiritual was within, among, and around us. Although I felt it and knew it for myself, it was not always easy to identify and often much more difficult to explain. Elusive and playful it might show itself unexpectedly, or be felt like the warmth of the

sun on skin as it peaks from behind a cloud. Envisioning the spiritual as animating life—being willing to read life *as* spiritual—is perhaps one way of opening oneself to possibilities for seeing.

To see anew is to be changed somehow, in the way one views something, or perhaps even in the way one lives new understandings. As I became immersed in the topic and in the stories told, I became more aware of the spiritual as it showed up in life. As I read the spiritual in the experiences of the children, I was prompted to reflect on my previous practice as a nurse. Learning was also realized in my role as an educator of nurses. More in tune with the spiritual, I have been able see it and name it as it showed up in how students practiced, providing an interpretation that perhaps raised their awareness of how the spiritual might be realized in their practice of caring for others. As I read the spiritual in the experiences of the children, my view of the spiritual expanded. More open to seeing the spiritual in the mundane, taken for granted aspects of life, I believe I am becoming more experienced. Gadamer (1975/2004) described being experienced as “tact.” When one is tactful, one is more skilled in moving around a topic, resulting in wise comportment in a given situation that relates back to the way we practice.

### **Implications for Research, Education, and Practice**

As a researcher seeking to broaden understanding of how ill children live the spiritual, I realize that there is an inherent responsibility to show how findings might be meaningful or useful to others. How will they flow from print to practice? Findings presented within the hermeneutic tradition are not meant to conceptualize or theorize and do not provide a prescription for doing things. Instead, the aim is to present an opportunity for seeing something differently and allowing that to change us. Within these findings, there is no claim of certainty of knowledge. Rather, providing a reading of the spiritual in the lives of particular children opens further possibilities for understanding. These understandings are never final or complete, for in an attempt to capture and confine the spiritual we lose the fullness and promise of what it could be. Similar to Amy as she wrestled her opponent, spirituality defies being pinned down. Attempts to do so only reduce and deflate it, like expelling breath from the lungs, leaving behind a tangible body, flat and lifeless, devoid of the animation the spiritual engenders.

To take up the findings and to see them as useful in practice, something revealed in them must resound within the reader. The words must echo something familiar that rouses to realization that which might be innately known, but perhaps lay hidden or long forgotten. At the very least, what is presented is an opening of possibilities, to see something that resonates, to play with ideas, and to try them out in light of one's own understandings and practice. In this trying out, dialogue ensues, within oneself and with others perhaps leading to further questions, fuelling an interchange of ideas that may extend possibilities beyond that which was initially presented. Overall, the study findings provide new understandings of how seriously ill children live the spiritual and provide possibilities for recognizing it and having meaningful conversations about the spiritual in pediatric healthcare practice. With this new knowledge, healthcare professionals may be able to initiate these conversations more easily and become more adept at recognizing the spiritual and with integrating the spiritual in their care.

In the context of institutional healthcare, spiritual care providers have a role to play. Perhaps their role is to initiate conversations about the spiritual with children or to support other caregivers in their attempts to do the same. Because spiritual issues may not be easily recognized by healthcare providers, it is possible that spiritual care providers are not always consulted when needs arise. At the same time, the spiritual does not wait for the arrival of spiritual care professionals. For children, signs of spiritual distress often appear at night when the spiritual care professionals are gone (Fulton & Murphy Moore, 1995). Spiritual distress may also arise when giving bad news or in times of suffering, crisis, or loss. Issues of a spiritual nature can arise at any time. Therefore, the findings of this study are helpful for any healthcare professional or parent in their spiritual care of seriously ill children by revealing clues for recognizing the spiritual and by providing guidance for initiating meaningful conversations about spiritual issues.

Although it might be reasonable to ask a child if they would like to talk to an expert, the child may be more comfortable talking about these issues with a professional they have an established relationship with, like the physician, nurse, social worker, psychologist, or child life specialist. This invitation into conversation could be initiated by any healthcare professional, educator, or parent who recognizes that a child's



behaviour is unexplainable, perhaps indicating deeper thoughts or concerns that remain unvoiced. This deeper engagement could also be initiated at times of crisis or loss, or at any time, and may even be prompted by questions posed by the child. Perhaps the best advice to caregivers is to be alert to the deeper meanings that might be hidden in children's expressions, to listen carefully, and not turn away or dismiss expressions that seem illogical. Asking open-ended questions about what children experience as spiritual, giving them time to contemplate, and appealing to their sense of awe and wonder instead of providing answers, allows children to use their imaginations in constructing a coherent narrative. Providing opportunities for narrative, artistic, and embodied expression of spiritual and existential issues may assist children to find meaning in their illness experiences and in their lives, leading to greater integration, wholeness, and health. Sharing these stories may also help other children begin to contemplate the spiritual in their own lives.

In my hope for this work to make a difference in the lives of others, I want to take it further, to play with ideas, and inspire others to do the same. While exploring the literature on childhood spirituality I began to see many shared understandings among scholars from various professions. Although there is a common interest in the spiritual with relation to child health and development, there also seems to be a lack of collaboration among professions and sectors that may stifle possibilities for greater understanding. Through the joining of minds and schools of thought, more progress can be made, leading to fuller and richer interpretations of the spiritual as lived by both healthy children and those with illness.

Perhaps this recognition of the spiritual in healthcare discourse will lead to practices that are more integrative rather than dis-integrative, and more holistic rather than mechanistic. Maybe a shared understanding of the spiritual will provide an opportunity to break down barriers between disciplines, professions, and sectors paving the way for collaborative research, education, and practice efforts and a greater understanding of the spiritual from diverse perspectives. For example, while many connections have been made between the spiritual and childhood resilience, the depth and character of this relationship remain unclear. Perhaps further exploration of this relationship is warranted. Scholars who practice and do research in the area of children's

mental health have also realized the importance of the spiritual in transformation and healing, yet there are still unanswered questions about how children live the spiritual and draw on this strength in times of suffering and trauma. Future studies that use hermeneutic phenomenology could help to answer some of these questions.

Scholars who practice in the area of child development and education seem to have amassed the most impressive collection of understandings of childhood spirituality as lived. Concerned with the holistic development of children, there has been a concerted effort to understand the spiritual as it shows up in children's everyday interactions. Because children spend a good portion of their day in school, this may be the ideal place to further explore and nurture the spiritual in children's lives. Although my research has focused on spirituality among children who are ill, we cannot ignore the contexts in which they live. They live in families and communities of others. They continue to live illness and the spiritual outside of hospitals and traditional institutions. Perhaps healthcare providers within these institutions would do well to consider expanding their practice outside of the walls that limit their seeing to one particular health context. Practicing outside these walls may also provide opportunities for promotion of children's health, perhaps with an aim to bolster resilience and minimize risk that could lead to future health problems.

The particularities of the lives of the children in this study provide understandings of the spiritual in the context of serious illness. The findings show how the spiritual is implicated in children's lives as they live illness. Still, much can be learned from future research in this area with the aim to broaden and deepen understandings of the spiritual in the lives of other children both ill and well. In the context of illness, future research exploring spirituality in other illness contexts or with other age groups would add to present knowledge. Including ill children with diverse cultural backgrounds would also extend understandings. More hermeneutic studies that explore childhood spirituality in various illness and cultural contexts and with children of different ages would add to understandings by providing more nuanced accounts of the phenomenon as lived.

It would also be helpful to investigate the long and short-term benefits of engaging children in conversations about spiritual issues. Although this study shows that

the spiritual was important in helping some children cope and make sense of a life beset by illness, it also indicates that the spiritual was implicated in the context of struggle. Longitudinal studies that explore children's lived experience of the spiritual and illness over time would provide further insight into how the spiritual is implicated as the trajectory of illness changes. Longitudinal designs would also provide a means of understanding how the spiritual is lived by children as they grow and mature and how engagement in meaningful conversations about spiritual issues help or hinder children's ability to live well with serious illness over time.

Future research that explores the spiritual among physically healthy children would also yield understandings that add to what is known. Although healthy children may not be living with the threats and limitations of illness, they still have to deal with everyday concerns and make sense of a world that is ever changing. They have to find a place within this world, a sense of self in relation in which the spiritual is implicated.

Interprofessional collaboration in future research exploring the spiritual among children would also lead to richer understandings and further integration of thought that transcends disciplinary boundaries. Perhaps combining research, education, and practice would also integrate these modes of learning that would help understandings flow more readily from print to practice. One possibility for realizing this integration may be in the way that health professionals are educated. For the sake of learning and practice, perhaps future research about childhood spirituality could be conducted in the context of interprofessional learning and practice experiences.

Although various research methods could be used to explore different aspects of the topic, hermeneutics provides one way of exploring the topic that allows for the integration of understandings from practice. As an interpretive methodology that is grounded in language, hermeneutic research may also assist learners in the health professions become more experienced in their communication with children and more adept at explicating spiritual meaning in their therapeutic relationships with them. With adult facilitation, the children become the teachers. They can teach each other and us about the spiritual and about ways of living well with illness within a community of others.

Given the lack of understanding of the spiritual among many healthcare professionals, this integration provides an avenue for bridging the gap between research, education, and practice that transcends professional boundaries. Researchers, educators, practitioners, and students from multiple fields of practice who are interested in the spiritual and holistic child health would be able to learn from the children and each other. Within an integrated, collaborative approach, professional students would have the opportunity to participate in research and receive guidance with interpreting the spiritual in children's experiences and lives and with responding in ways that facilitate deeper thought and openings for possibilities.

I end this thesis with the hope that this work will prove meaningful. For me, the writing of this thesis has broadened and deepened my understandings of childhood spirituality, providing meaning, purpose, and direction for my work. Born from a concern for the lack of the spiritual in healthcare, perhaps there will be opportunities to extend this work beyond the thinking and writing to a place where it can make a difference in the lives of both ill and healthy children and for those who care for them.

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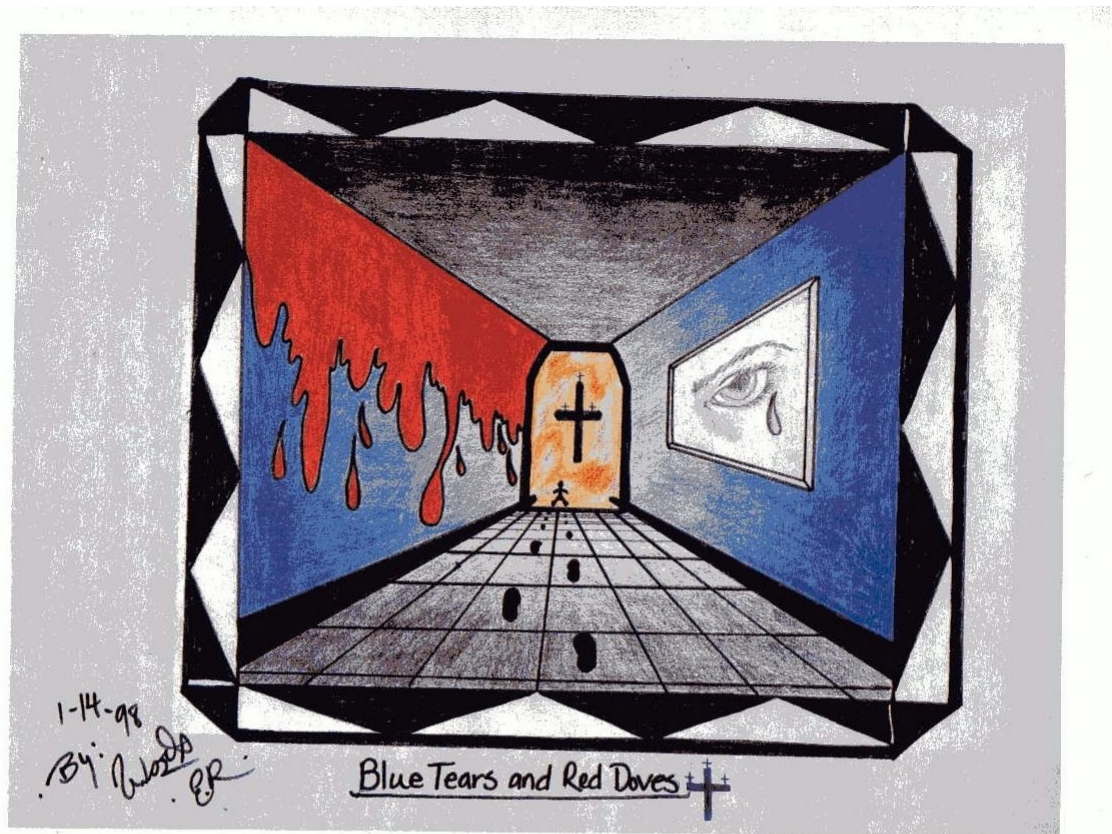
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## Appendix A: Expressions of a 16-Year-Old Female with Cancer<sup>2</sup>



Cancer. Female, 16 years old. **Blue Tears and Red Doves**, 1998. Pencil & felt markers, 12 x 14"

Hall of Darkness  
Hall of Pain  
Walls of death and sorrow  
Hide behind the paint  
Walking down this hall of emptiness  
Walking down this hollow cave  
I saw four red doves flying away  
I wondered why they left me  
I wondered why they couldn't stay  
While walking down this "nothing" path  
I felt all alone and irate/ Blue tears fell from my eyes  
In a blue hall I was left to die  
I held it in and wiped my eyes  
I picked myself up and walked what felt like a thousand miles  
When to my surprise I saw a light  
It was the end of the hall  
It was the doorway to life/I had finally felt free again  
I had finally felt alive  
I will never forget my journey and those four red doves of mine  
For now we are binded together  
Together 4ever till the end of time.

<sup>2</sup> The image above is from *Childhood Revealed: Art Expressing Pain, Discovery and Hope* (p. 149), by H. S. Koplewicz and R. F. Goodman (Eds.), 1999, NY, New York: Harry N. Abrams, Inc. Copyright 1999 New York University by Harry N. Abrams, Inc. Reprinted with permission.

## Appendix B: Introductory Letter to Families



### Spirituality among Children with Cancer and Cystic Fibrosis

Date:

Dear parent/guardian:

My name is Holly Richardson. I am a graduate student at Dalhousie University. I am working with Dr. \_\_\_\_\_ on the research study named above and I would like to invite your child to participate. Enclosed you will find information about the study. You may want to review the study information with your child and give guidance to help him/her make a decision about participating. Please feel free to contact me if you or your child has any questions about the study or if you want to set up a time for me to meet with you and your child.

If you prefer not to take part in this study, please contact me and I will take your name off the list. My phone number is (902) 473-8437 and my email address is [holly.richardson@dal.ca](mailto:holly.richardson@dal.ca).

If I do not hear from you in about two weeks, I will give you a call. If your child is interested in being in the study, we can set up a time to meet. At that time, I can also answer any questions you or your child might have. If your child decides not to be in the study, it will not affect the care that your child or your family members receive from the IWK Health Centre in any way.

Thank you for your time and consideration.

---

Holly Richardson  
Doctoral Student  
Interdisciplinary PhD Program  
Dalhousie University

---

Dr. Conrad Fernandez or Dr. Dan Hughes  
Ped. Hematologist/Oncologist or Pulmonologist  
IWK Health Centre  
Dalhousie University



## Appendix C: Parent Authorization Form



### Spirituality among Children with Cancer and Cystic Fibrosis

**Date:**

**Researchers:**

Principal Investigator:

Holly Richardson, RN. Graduate Student, Interdisciplinary PhD, Dalhousie University

Co-investigators:

Michael Ungar, PhD. Social Work, Dalhousie University (PhD Supervisor)

Deborah McLeod, PhD, RN. School of Nursing, Dalhousie University

Christine Chambers, PhD. Psychology, IWK Health Centre, Dalhousie University

Rev. Nancy Cocks, PhD. Theology, formerly with the Atlantic School of Theology

Conrad Fernandez, MD. Pediatrics, IWK Health Centre, Dalhousie University

Dan Hughes, MD. Pediatrics, IWK Health Centre, Dalhousie University

This study is supported by a grant from The Nova Scotia Health Research Foundation.

#### **Introduction:**

My name is Holly Richardson. I am a graduate student at Dalhousie University. I am also a nurse and a teacher of nursing. In my role as a graduate student, I am doing a research study (named above) as part of my school program. Your son/daughter is being invited to take part in this study and this form provides information about the study. Before you help your child decide about taking part, it is important that you understand: the purpose of the study, the risks and benefits, and what your son/daughter will be asked to do.

Your son/daughter does not have to take part in this study. Taking part is totally up to him/her (with your permission). Your child's decision to take part starts with the first contact about the study and continues until the end of the study. Your child may decide not to take part or may decide to stop taking part in the study at any time. This will not affect the care your child or your family members receive from the Izaak Walton Killam (IWK) Health Centre in any way. If you or your child has any questions about the study, I will be available to answer them at any time.

### **Why are the researchers doing this study?**

The purpose of this study is to learn more about young people's spirituality. Specifically, we would like to know what spirituality means to young people and how it plays a part in their lives and in their health. For the purpose of this study, spirituality is not the same as religion. For some, religion may be a big part of spirituality. For others, spirituality may not include religion at all. Spirituality can mean different things to people. That is why we would like to know more about what young people think.

Unfortunately, there is not a lot known about young people's spirituality. Even less is known about what spirituality means to young people who live with a chronic illness. This study may teach us more about what spirituality means to young people with cancer and cystic fibrosis. I hope that with more knowledge, we can help support this part of young people's growth.

### **How will the researchers do this study?**

This study will include ten young people from the Maritime Provinces (5 girls and 5 boys) who are 9-14 years of age. All participants will be receiving treatment at the IWK for either cancer or cystic fibrosis. Each young person will be asked to meet and talk with me two to three times. Each meeting will last for about one to two hours and will be spread at least two weeks apart (total time 3-6 hours). The meetings can be held at the IWK Health Centre during a scheduled visit or at your home. Each conversation with your child will be recorded and compared with what is said by other young people in the study.

### **What will your child be asked to do?**

Your child will be asked to meet with me two to three separate times. During the first meeting, I would like to review the consent form with you and your child. If there is agreement to take part, I will begin the first meeting with getting to know your child. I will focus mainly on their relationships with family, friends, and healthcare givers. We will also talk about things that are important in his or her life.

Next, I will ask him/her to share stories about what it is like to live with illness. I will also ask what he/she thinks spirituality is. In addition to talking, your child will be asked to draw pictures or write poetry about things we discuss. Your child may choose not to draw or write poetry. Your child may decide just to talk and that is his/her choice. Enclosed you will find a copy of some of the questions I might ask your child. Although the study plan allows for three interviews, it may only take two interviews to complete all of the questions.



Each conversation with your child will be digitally recorded. This recording will be typed. At the beginning of the second and third meetings, (if a third meeting is needed) I will review with your child the main things we talked about at the last meeting. At a convenient time for you and your child, I will also contact your child by phone after the last face-to-face meeting. This is to check that I have correctly recorded the main themes of our conversations. This will take about 15 minutes. Your child can also change or remove any information they wish (Note: This was not done because findings arrived at through this methodology are not verified in this way. Rather, the findings were interpretative. Meanings were co-created rather than corroborated through member checking.)

Your child will also be asked if their artwork and direct quotes from our conversations can be used when I tell other people about this study in an anonymous way. No one will know the words or art work are from your child.

### **What are the burdens, harms, and potential harms?**

Talking about experiences of living with illness might cause your child to become upset. If this is the case, emotional and spiritual support can be provided by your IWK Healthcare Team. Please contact one of your care team members for referral or contact the psychosocial/spiritual care providers directly using the contact information provided at the end of this form.

Your child will be reminded before each meeting that if he/she feels uncomfortable or wants to stop the conversation, this can be done at any time. Your child can also decide to stop taking part in the study if he/she wishes.

Taking part in the study means your child will have to take time to meet with me. I will check with you the day before the meeting to make sure that it is still a good time to meet. If not we can arrange another time.

At the end of the study, I will ask your child what it was like taking part in the study. I will also ask if they are in need of emotional support and will direct them to you and/or the Healthcare Team if necessary.

### **What are the possible benefits?**

Talking about things that are important in your child's life could be a positive experience. Talking about living with illness might help your child to make sense of things in his/her own mind. It may also prompt conversations with you about things that matter to him/her. Taking part in this study might not help your child personally. However, we might learn things that will be of future help to other young people living with illness.

**What alternatives to participation does my child have?**

There are no alternatives to taking part in this study. Taking part in this study is totally up to your child (with your permission). If your child decides not to take part in this study, it will not affect the care your child or family receives from the IWK Health Centre in any way.

**Can your child withdraw from the study?**

Yes, your child can withdraw from the study at any time. Your child can also decide to remove his/her information from the study before it is published. If your child decides to stop being in the study, this will not affect the care your child or family receives from the IWK Health Centre in any way.

**Will being in this study cost anything and, if so, how will I/my child be reimbursed?**

Taking part in this study will not cost your family any money. However, it will mean giving up some of your time. To thank your child for taking the time, I will give him/her the art supplies used in the study (whether they are used by your child during the study or not).

**Are there any conflicts of interest?**

The researchers have no conflicts of interest to declare.

**What about possible profit from commercialization of the study results?**

No money will be made from doing this study.

**How will I/my child be informed of study results?**

If your child wishes, he/she will be given a typed copy of the conversations we have together. He/she can also request a summary of the study results. If you wish, I can also send you a summary of the study results but not a copy of the conversations. If you provide an address on the authorization form, I will be able to mail these to you.

## **How will my child's privacy be protected?**

The things your child says (direct quotes) during our talks may be used in writing the story of the research but his/her name will not be used. Any direct quotes will be reported in such a way that your child cannot be identified. For your child's privacy, he/she will be asked to pick a fake name for the study that will replace his/her real name. Real names will not be used when I talk about this study with others. A paper that has both your child's real name linked to his/her fake name will be kept in a locked drawer in Dr. Fernandez's office. Your child's name will not be used in any public display of this study. If your child does artwork as part of this study, these items will be used to tell other people about the study only if your child agrees. A final report will be written about the main ideas that are talked about but we will not reveal individual participants' identities.

No one except your child's primary service physician and me will know your child was involved in the study unless your child wants to tell him or her. The typed copy of conversations with your child will be seen only by the research team and me. Doctors from your child's healthcare team at the IWK (Either Dr. Conrad Fernandez or Dr. Dan Hughes) know about the study and will know that your child will be involved in the study.

All data will be kept safe on a password protected portable hard drive. This hard drive will be kept in a locked drawer in my office to make sure no one can look at it without asking me. No recordings of conversations with your child will be sent over the web. Five years after publication of the study, all information that identifies your child will be destroyed.

If your child wishes, he/she can choose to have you with him/her during our talks. Otherwise, things your child says will not be shared with you unless he/she wishes for you to know. Some children may share more openly if a parent is not there. Other children will feel more comfortable sharing if a parent *is* there. This is totally up to your child.

Please note that, in the rare event that we should learn anything during the course of your child's participation in our study that would cause us to believe that your child is in danger of harming him/herself or others, Dr. Fernandez or Dr. Hughes would follow-up with you directly. Further, in accordance with provincial laws, in the rare event that we learn anything during the course of your child's participation in our study that would cause us to believe that your child was being harmed; we would be required to report this to a child protection agency. If any issues do arise because of your participation in this study, you are encouraged to contact Dr. Fernandez at (902) 470-7290 or Dr. Hughes at (902) 470-8218.

### **What if I/my child have study questions or problems?**

You or your child can ask questions about the study at any time. You can email me at [holly.richardson@dal.ca](mailto:holly.richardson@dal.ca) or call me at (902) 473-8437. I will check messages daily from Monday to Friday and I will get back to you within 24 to 48 hours (except weekends). If you have any questions at any time during or after the study about research in general, you may contact the Research Office of the IWK Health Centre at (902) 470-8765, Monday to Friday between 9 am and 5 pm.

### **What are my child's research rights?**

By signing this form, you are showing that you are satisfied that you understand what is being done in the study. You are also saying that you give authorization for your child to take part in this study. This also means that you have helped your child make a decision about taking part. You and your child have a right to have a good understanding of the study. This includes an understanding of what is expected of him/her and of the good and bad things that might happen. With your help, your child must be able to make a personal decision to be in the study. This decision must be freely chosen by your child.

By signing this form, you are not waiving yours or your child's legal rights. Giving your authorization does not release the sponsors, researchers or their institutions from their legal and professional duties to your child and family. If your child becomes ill or injured because of taking part in this study, help will be available to you and your child at no extra cost. Your child is free to stop taking part in the study at any time without fear that your family will not get the healthcare you are entitled to receive.

***If you have any questions at any time during or after the study about research in general you may contact the Research Office of the IWK Health Centre at (902) 470-8765, Monday to Friday between 9a.m. and 5p.m***

## Contact Information for Researchers:

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**IWK Collaborator**  
**Co-Investigator**  
Department of Pediatrics,  
Respiratory Division  
Dalhousie University and IWK  
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Email: [dan.hughes@iwk.nshealth.ca](mailto:dan.hughes@iwk.nshealth.ca)

**Psychosocial and Spiritual Care Services  
IWK Health Centre**

**Spiritual Health Services**

Glenn Breen  
Ecumenical Chaplain  
IWK Health Centre  
Email: [glen.breen@iwk.nshealth.ca](mailto:glen.breen@iwk.nshealth.ca)  
Phone: (902) 470-7772

**Psychosocial Health Services**

Dr. Mark Blumberg PhD  
Hematology/Oncology/Nephrology and Brain Tumor Clinic  
IWK Health Centre  
Email: [marc.blumberg@iwk.nshealth.ca](mailto:marc.blumberg@iwk.nshealth.ca)  
Phone: (902) 470-8454

**Parent Authorization Form**



**A Phenomenological Exploration of Spirituality and Meaning-Making in the Context of Childhood Cancer and Cystic Fibrosis (Spirituality among Children with Cancer and Cystic Fibrosis)**

**Child's Initials:** \_\_\_\_\_

**Parental Authorization:**

I have read, or had read to me, this information and authorization form. My child and I have had the chance to ask questions which have been answered to my satisfaction before signing my name. We understand the nature of the study and the potential risks. I understand that I have the right to withdraw my child from the study at any time without affecting my child or family's care in any way. I have received a copy of the Information and Consent Form for future reference. I freely agree that my child can participate in this research study.

\_\_\_\_\_  
Parent's Signature

\_\_\_\_\_  
Date/Time

\_\_\_\_\_  
Parent's Name (Please Print)

**STATEMENT BY PERSON PROVIDING INFORMATION ON STUDY**

I have explained the nature and demands of the research study and judge that the participant named above understands the nature and demands of the study.

\_\_\_\_\_  
Name (Print)/Position

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date/Time

**STATEMENT BY PERSON OBTAINING CONSENT**

I have explained the nature of the consent process to the participant and judge that they understand that participation is voluntary and that they may withdraw at any time from participating.

\_\_\_\_\_  
Name (Print)/Position

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date/Time

**Parent Authorization Form**



**A Phenomenological Exploration of Spirituality and Meaning-Making in the Context of Childhood Cancer and Cystic Fibrosis  
(Spirituality among Children with Cancer and Cystic Fibrosis)**

**Child's Initials:** \_\_\_\_\_

**How do you want me to use your child's information in the future?**

The following indicates your authorization for use or receipt of study information in the future. You may change your mind about this at any time.

**Please initial and indicate "Yes" or "No" to each of the following prior to signing your name:**

\_\_\_\_\_ I would like to have a summary of the study results. If you answer yes, please provide your email or mailing address.

**Address:** \_\_\_\_\_

\_\_\_\_\_ I give authorization to contact my child and me again in the future to ask about interest in participating similar studies. If you answer yes, please provide your phone number.

**Phone:** \_\_\_\_\_

\_\_\_\_\_ I give authorization to use my child's direct quotes and artwork in a confidential way in future studies.

\_\_\_\_\_ I give authorization to use my child's direct quotes and artwork in a confidential way for teaching other healthcare workers.

\_\_\_\_\_  
Parent's Signature

\_\_\_\_\_  
Date/Time

\_\_\_\_\_  
Parent's Name (Please Print)



## Appendix D: Child Assent Form



### Spirituality among Children with Cancer and Cystic Fibrosis

#### **Introduction:**

My name is Holly. I am a student at Dalhousie University. I am also a nurse and a teacher of nursing.

#### **Why are we doing this study?**

We want to learn more about spirituality. We want to know what it means to young people who have or have had a serious illness. Spirituality can mean many things. It is different for everyone. We would like to know what it means in your life.

The things learned from this study may be used in many ways. We will write reports for health journals. We may also write stories for newspapers, or make pamphlets or posters. We might even share information on radio talks, podcasts, or on a website. You will not be named in any report.

#### **What will happen during this study?**

During the first meeting, I will answer any questions about the study that you have. Then I will start by asking about important people and things in your life. I would also like to ask you to share stories about what it is like to have lived with your illness. I will also ask what you think spirituality is and what it means to you. There is no one right answer. It is what *you* think. I will also ask you to draw pictures or write poetry about things we discuss. You do not have to draw or write poetry. You can just talk. It is totally up to you.

Each talk I have with you will be tape-recorded. It will then be typed. At our next meeting, I will review the main things we discussed. I want to check to make sure what is written is what you meant to say. You can then change your information at any time. If you want, you can have a typed copy of our talks. You can also have a report about what was learned in the study. You will also be asked if your artwork and words can be used when I talk and write about the study. No one will know the words or art work are from you.

## **Are there any good or bad things about this study?**

*These bad things could happen:*

Talking about things that happen in your life might make you feel angry, sad, or scared. If this happens, there are people who can help you. If you want, you can tell your parents. You can also tell your doctor or one of the other team members at the IWK. They can then get you the support you need.

You can stop our talks at any time. No one will be upset if you do not want to talk anymore. You might find the meetings too long. You can stop the meetings when you want.

*These good things could happen:*

Talking about important people and things might make you feel good inside. It might also help you sort out your thoughts and feelings. This study might not help you personally at all. What we learn from this study could help other young people in the future.

## **Who will know about what I did in this study?**

No one except me, and the researchers helping me, will know what you did in the study. No one else will know unless you want to tell. The typed copy of our talks will be seen by only me, and the researchers helping me. You can have a copy too, if you want.

When I write the story of the research, I will use some of your exact words. I will not use your real name when I write or talk about the study though. I also will not give details that could identify you. For your privacy, I will use a fake name that you can choose. A paper with your real name and fake name will be kept safely in the doctor's office.

No one will be able to look at your information without asking me. No recordings of our talks will be sent on the web. If you wish, you can have someone with you during our talks. Otherwise, things you say will not be shared with your parents.

The only exception is that if you talk about being hurt or abused by someone, I have to report this.

## **Do I have to be in this study?**

You do not have to be in this study. Being in the study is totally up to you (your choice). You can change your mind at any time. No one will be upset if you do not want to be in the study. Not being in the study will not affect the care you get from the IWK.

## **What if I have questions?**

You can ask me anything about the study you want to know. I will answer your questions any time. My phone number is (902) 473-8437. My email is [holly.richardson@dal.ca](mailto:holly.richardson@dal.ca).

## Appendix E: Letters of Support



### A Phenomenological Exploration of Spirituality and Meaning-Making in the Context of Childhood Cancer and Cystic Fibrosis

August 22, 2008

Dear REB Committee Members:

This letter is to confirm that I have been informed about the above study and that I am aware of the potential need for increased psychosocial care service use by study participants. I am prepared to provide psychosocial support to pediatric oncology study participants based on identified need. Either families can contact me directly or I can be consulted by other health team members.

Sincerely,

---

Dr. Marc Blumberg, PhD  
Hematology/Oncology/Nephrology and Brain Tumor Clinic  
IWK Health Centre  
Email: [marc.blumberg@iwk.nshealth.ca](mailto:marc.blumberg@iwk.nshealth.ca)  
Phone: (902) 470-8454



## **A Phenomenological Exploration of Spirituality and Meaning-Making in the Context of Childhood Cancer and Cystic Fibrosis**

March 24, 2009

Dear REB Committee Members:

This letter is to confirm that I have been informed about the above study and that I am aware of the potential need for increased psychosocial care service use by study participants. I am prepared to provide psychosocial support to pediatric study participants with cystic fibrosis based on identified need. Either families can contact me directly or I can be consulted by other health team members.

Sincerely,

---

Michelle Brake, MSW on behalf of:  
Nancy Rogers-Currie, MSW  
Cystic Fibrosis Team  
IWK Health Centre  
Email: [nancy.rogerscurrie@iwk.nshealth.ca](mailto:nancy.rogerscurrie@iwk.nshealth.ca)  
Phone: (902) 470-8077



## **A Phenomenological Exploration of Spirituality and Meaning-Making in the Context of Childhood Cancer and Cystic Fibrosis**

August 22, 2008

Dear REB Committee Members:

This letter is to confirm that I have been informed about the above study and that I am aware of the potential need for increased spiritual service use by study participants. I am prepared to provide spiritual support to study participants based on identified need. Either families can contact me directly or I can be consulted by other health team members.

Sincerely,

---

Glenn Breen  
Ecumenical Chaplain  
IWK Health Centre  
Email: [glen.breen@iwk.nshealth.ca](mailto:glen.breen@iwk.nshealth.ca)  
Phone: (902) 470-7772

## Appendix F: Interview Guide



### A Phenomenological Exploration of Spirituality and Meaning-Making in the Context of Childhood Cancer and Cystic Fibrosis

#### (Spirituality among Children with Cancer and Cystic Fibrosis)

#### Interview One

##### **Introductions and Acknowledgements:**

Upon meeting the child and family, I will introduce myself and give thanks for their interest. I will also thank the children for taking the time to share their stories. I will then remind them that I'm there as a student and I'm hoping to learn more about spirituality and about what it's like to be a young person who's ill.

##### **Explanation of Study and Agreement to Take Part (Assent/Authorization):**

Next, I will obtain parental authorization and child assent. This conversation will involve me, the child, and at least one parent/guardian. First, I will ask if they read the letter of invitation and authorization/assent information and entertain any questions about the study. I will clarify any misunderstandings and welcome discussion. With their agreement, I will then review each part of the assent form while asking the child about what they think that means. Getting the child to repeat it in their own words will help me determine their understanding.

Once all questions have been answered to the child and parent's satisfaction, I will ask the parent(s) to sign the authorization form and give them a copy to keep. Given that signing a form may be viewed as being overly formal, I will comment on this and remind the child and parent that just because a form was signed doesn't mean they can't stop being in the study at any time. I will later document the conversation in a log indicating child assent.

## **Beginning the Conversation:**

Before beginning with the first interview, I will ask the child who he/she would like to have there during our talk or if they would rather talk with me alone. This initial engagement will be a time for getting to know the child, for making connections, and for establishing a sense of comfort with being in a new situation. I will also position myself as a learner to help offset the inherent power imbalance between researcher and child.

### Interview Prompts:

#### Getting to know the child:

- What do you like to do in your spare time?
- What do you like most about (this activity/activities)?
- Who are the important people in your life?
- Whom do you talk to when you have concerns or worries?
- Tell me about a special time you spent with (Names).

Initial discussion will center on children's positive relationships with the environment and with significant others while prompting stories about experiences of activities and events. Asking about significant relationships and experiences in children's lives is important because it points to those aspects of their lives that have value and meaning. Knowing to whom children talk to in times of need also gives insight into natural support systems.

#### Meaning of illness:

1. What is it like to have/have had cancer/cystic fibrosis at your age?
2. What is it like going to school?
3. What is it like at home?
4. What is it like going to the hospital?

I might also ask them to tell me about a really good day or a really bad day they may have had in any of the above situations.

#### Meaning of spirituality/religion:

1. Have you heard the word "spirituality" before? What does this mean for you?
2. Do you follow a certain religion? If so, tell me about how your religion relates to your spirituality.

If the child gives affirmative answers to one or both of the above questions, I will ask:

3. How did you learn these things about spirituality/religion?
4. Tell me about a time when you felt spiritual/religious.
5. What part do your spiritual/religious beliefs play in your life? What part do these beliefs play in dealing with your illness?

I will remind the children that spirituality could mean different things to different people and that there is no right answer. I will let them know that I am interested in what *they* think. These questions recognize the legitimacy of children's knowledge and seek to understand how they gained this knowledge and how their beliefs are manifested in their lives.

Conversation will be emergent and I will elicit stories from children about people and things they deem as important in their lives. If any questions do not prompt engagement in discussion, I will observe for signs of misunderstanding and/or dissent and proceed with reframing the question or with addressing the child's level of comfort. I will also offer the child an opportunity to draw or write a poem or story about something we discussed. This can then be used to stimulate further conversation.

This will conclude the first interview and I will summarize the main points of our conversation to verify that my understanding is correct. I will then thank the children and ask about their willingness to meet again. If they agree, I will involve the parents in discussion about a convenient time and place to meet again. In parting, I will ask the child to think about what we talked about, to write stories or poems or draw pictures about it if they wish and I will leave the art supplies with them. I will also encourage them to call or email me if they have any questions about the study, if they change their mind about meeting again, or if they need to reschedule.

## **Interview Two**

### **Re-acquaintance and Settling In:**

This will include greetings and establishment of who is to be present during the interview. I will then get their permission to record our conversation and re-confirm assent. Given the children's previous experience with the study, I will ask what it was like for them taking part so far and what they felt like after we talked. This will alert me to any adverse responses or possible cues of dissent. In these circumstances, I will address these issues and any other questions before proceeding.

After getting a sense of their experience with the last interview, I will describe the focus of the second interview and inquire about their willingness to proceed. I will also remind the children that they can stop the interview at any time by saying "I don't want to talk anymore."

### **Beginning the Conversation:**

I will begin with a review of the main themes arising from our last conversation and ask for verification that I "got it right." (Note: Verification of meaning was not obtained in this way. Instead, I summarized the previous interview to prompt new thought and to direct further questioning.) I will also ask the children if they thought any more about what we talked about and if they have anything to share. If the children do not have



anything to share, I will proceed with questions that focus on how the children see themselves in relation with self, other, and world and how living with chronic illness may have changed the way they live their lives.

#### Interview Prompts:

##### Relationship with Self and Others in Time:

1. Tell me what you imagine your life to be like when you get older.
2. What hopes do you have about the future?
3. How do you want to live your life?
4. What kind of person do you want to be?
5. Has your illness changed the way you look at life? Has it changed the way you see yourself? Has it changed the way others treat you?
6. How do you think people should treat each other?

##### Coping with Illness:

7. Tell me what you find challenging about your illness? How have you dealt with these challenges?
8. What supports do you use when you need help dealing with things?
9. Tell me about a time when you needed help dealing with things. What did you do? Who helped you?
10. Tell me about a time when you were successful in dealing with challenges of your illness.
11. Tell me about a time when things did not turn out so well.
12. Tell me about a time when you helped someone else.
13. If your best friend had cancer/cystic fibrosis, what would you do to support them?

If any questions do not prompt engagement in discussion, I will observe for signs of misunderstanding and/or dissent and proceed with reframing the question or with addressing the child's level of comfort. I will also offer the child an opportunity to draw or write a poem or story about something we discussed. This can then be used to stimulate conversation. I may also use other prompts (i.e. YouTube video depicting the relationship between a crow and a kitten <http://jfsdaily.com/?p=55>) to stimulate conversation.

At the end of the interview, I will thank the children and ask about their willingness to meet again. If they agree, I will involve the parents in discussion about a convenient time and place to meet again. In parting, I will ask the child to think about what we talked about, to write stories or poems or draw pictures about it if they wish. I will also encourage them to call or email me if they have any questions about the study, if they change their mind about meeting again, or if they need to reschedule.

## Interview Three

**Re-acquaintance and Settling In:** See Interview 2.

### **Beginning the Conversation:**

I will begin with a review of the main themes arising from our last conversation and ask for verification that I “got it right.” (Note: Verification of meaning was not obtained in this way. Instead, I summarized the previous interview to prompt new thought and to direct further questioning.) I will also ask the children if they thought any more about what we talked about and if they have anything to share. If the children do not have anything to share, I will proceed with questions that focus on how the children see themselves in relation with self, other, world and the Transcendent.

Interview Prompts:

#### Relationship with the Surrounding World:

1. Imagine a perfect world. Tell me what you think it would be like.
2. Tell me about a time in your life when everything was right with the world and you felt really good inside.

#### Relationship with the Transcendent:

3. How do you think the earth was made?
4. How do you think we (people) got here (on earth)?
5. Do you think we have a purpose here? Why do you think we are here?
6. Do you ever feel like someone or something is looking out for you/guiding you/helping you? Tell me about a time when you felt this way.
7. Have you ever felt really close to someone or something? Tell me about a time when you felt this way.

If any questions do not prompt engagement in discussion, I will observe for signs of misunderstanding and/or dissent and proceed with reframing the question or with addressing the child’s level of comfort. I will also offer the child an opportunity to draw or write a poem or story about something we discussed.

### **Terminating the Relationship:**

At the end of the interview, I will remind the children that this is our last face-to-face talk together. I will thank them for taking the time and for all the things that they shared. I will also ask if I can contact them by phone or email to verify the main themes of our conversations to make sure I got what they said right. I will confirm this is acceptable to their parents. (Note: Meanings/understandings were not confirmed in this way—they were co-created. Confirming meaning by member checking is counterintuitive to the methodology used in this study.)

## **Appendix G: Poems**

### **Beginning of the Book By Lisa Joyce (Age 17)**

*The world is there for you to explore  
To show your strengths, beliefs and more.*

*In the beginning we know very little  
As time goes on life becomes a riddle.*

*Our feelings we will let be known  
The ones we've gathered as we have grown.  
And so this book will help you understand  
So that you might lend us a helping hand.*

### **Cancer...The Fight By Lisa Joyce (Age 17)**

*Cancer is a terrible thing  
It hurts the world and gives it pain  
With bitterness, anger, fear and rage  
A battle that must be won*

*No matter what the age  
Don't keep it in  
Let the pain come out  
Feel free again*

*You can't always win all by yourself  
Let others give you a hand  
Beat the anger, feel free to cry  
Let the true you show through*

*Nurses only try to help  
They're there to give you aid  
To help you with your daily drugs  
They'll even give you hugs*

*Nurses, yes they'll all be there  
In sorrow and in pain  
To get you through the hardest times  
The sunshine and the rain*

*Keep up your strength  
Your blood counts too  
You know chemo fights  
But so must you*

**Faith**  
**By Lisa Joyce (Age 17)**

*I sat all alone  
I sat and thought why?  
Why am I sick?  
Why am I ill?*

*I sat with the Lord  
We talked some more  
Why I was sick?  
Why I was ill?*

*I sat with the Lord  
To understand why  
Who made me sick?  
Who made me ill?*

*I sat with the Lord  
I sat with myself  
I sat with my illness  
And understood why.*

(Joyce, 1990)

## Appendix H: Copyright Permission Letter

January 16, 2013

**Re:** Koplewicz, H. S., & Goodman, R. F. (Eds.). (1999). *Childhood revealed: Art expressing pain, discovery and hope*. NY, New York: Harry N. Abrams, Inc.

Harry N. Abrams, Inc.  
100 Fifth Avenue  
New York, N.Y. 10011  
[www.abramsbooks.com](http://www.abramsbooks.com)

I am preparing my Doctoral thesis for submission to the Faculty of Graduate Studies at Dalhousie University, Halifax, Nova Scotia, Canada. I am seeking your permission to include a copy of the following image as an appendix in the thesis:

“*Cancer*. Female, 16 years old. **Blue Tears and Red Doves**, 1998. Pencil & felt markers, 12x14”

Canadian graduate theses are reproduced by the Library and Archives of Canada (formerly National Library of Canada) through a non-exclusive, world-wide license to reproduce, loan, distribute, or sell theses. I am also seeking your permission for the material described above to be reproduced and distributed by the LAC(NLC). Further details about the LAC(NLC) thesis program are available on the LAC(NLC) website ([www.nlc-bnc.ca](http://www.nlc-bnc.ca))

Full publication details and a copy of this permission letter will be included in the thesis.

Yours sincerely,

Holly Richardson

---

Permission is granted for:

- 1 the inclusion of the material described above in your thesis.
- 2 for the material described above to be included in the copy of your thesis that is sent to the Library and Archives of Canada (formerly National Library of Canada) for reproduction and distribution.

Name: \_\_\_\_\_ Title: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_