“It’s not just camp”: Understanding the Meaning of Children’s Cancer Camps for Children and Families.

by

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A THESIS

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Abstract

In response to the stress of the childhood cancer experience, children’s cancer camps arose in the 1970s as a way for children and their families to escape the rigidity and severity of cancer treatment. Cancer camps are designed to meet the needs of the whole family at each stage in the cancer experience—from diagnosis through treatment, to survival or bereavement. In 2008, the eight camps across Canada provided specialized oncology camps and community support programs to 5,252 children and their families—a 10% increase from the previous three years. As more children are surviving childhood cancer, the need for specialized camps and community programs continues to grow.

My purpose in this philosophical hermeneutic inquiry was to understand the meaning of children’s cancer camps for the child with cancer and the family. Six childhood cancer families and five cancer camp counselors were interviewed in order to bring understanding to this topic. Findings from this research revealed that camp means different things for different families, and that much is at play in the cancer camp experience: finding acceptance and fit, grief as something to live with versus “get over,” storytelling as a means of re-shaping and understanding traumatic experiences, and the solidarity of the community as one that creates intense, healing bonds.

Children’s cancer camps, I conclude, need to be considered a necessity, versus a luxury, and should even be thought of as a psychosocial intervention for some children and families. Barriers such as structure of funding and access to resources are present, and likely due to the separate-ness of camps from hospital programs.

In addition, this research speaks to the need for interpretive methods like hermeneutics to incorporate a tool such as Social Return on Investment, a principles-
based approach that values change that would not otherwise be valued, when questions of social value are present.
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Dedication

To the children and families who experience childhood cancer,

you are my life’s work.
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Chapter One: The Call of the Topic

Sitting in a lecture theatre in the second year of my undergraduate nursing degree, I was just another face in the crowd of hundreds staring back at the professor. By all accounts, there was nothing special about this day; it was just another class, and I was just another student. Indeed, there was nothing unusual about that day – except for the fact that it became a defining moment in my life. On that day, something found me and changed my path in life. It was during an innocuous, short film shown in class about children with cancer attending summer camp that I was claimed. As this was the early 1990s, the film was not particularly sophisticated by today’s standards, nor was it overly substantive in content. It was a simple film showing children with cancer attending camp, supplemented by interviews with several children, and nurses who were attending as camp counselors. The superfluous details of class and context are forgettable, yet I will never forget this moment in time when pediatric oncology chose me.

Gadamer (1960/1989) stated that understanding begins when something addresses us, when it picks you out of a crowd and chooses you, invites you into its world of past and present. Sometimes this address is so strong and powerful that you become a part of it and it a part of you. Gadamer called this authenticity – when you become lost to something such that it changes who you are. You become beholden to its what-ness and that-ness, powerless within its grasp and open to its influence.

Some people enter doctoral studies with a clearly defined research question. They come with a passion for a particular phenomenon knowing exactly on what they will focus. This was not my experience. In deciding where to position my doctoral studies, it became clear to me that my passion for pediatric oncology made choosing a topic much
like choosing a favorite child – it seemed impossible. I spent many hours “trying on”
different ideas, searching for gaps in the literature, and discerning where my contribution
to the field was best suited. I wish I could say I had an epiphany (or at least an
enlightened moment), but I did not. Ultimately, it took a suggestion from a colleague for
me to choose my topic. Lamenting on my difficulty finding a research topic, she
suggested that I study the meaning of children’s cancer camps on children and their families. Given that she was the founder and Chief Executive Officer of the local charity
that funds and hosts these camps, she had a vested interest in suggesting this topic,
however, the more I thought about it, the more I realized the perfect fit this topic had with me – it was a cancer camp that claimed me in the first place.

Significance and Prevalence

In Canada, approximately 1400 children and adolescents under the age of 20
develop cancer each year (Canadian Cancer Society, 2012). Three-year survival rates are
reported at 82% (Canadian Cancer Society, 2008), with the mortality rate being
approximately one-sixth the incidence rate. Improvement in childhood cancer survival
rates can be attributed to enhanced diagnostic procedures, multi-modal therapies (e.g.,
chemotherapy, radiation, surgery, and blood and marrow transplantation), and the
centralization of care and support services (Canadian Cancer Society, 2012). The
improvement in survival rates, however, is not without a cost; disruptions in family life,
financial and employment difficulties, marital stress, generalized uncertainty, changes in
routines, roles and relationships, life long side effects, and disruptions and restrictions in
daily life are only some of the stressors that affect these families (Packman, 1999; Scott-
Findlay & Chalmers, 2001; Woodgate, 2006).
In response to the stress of the childhood cancer experience, children’s cancer camps arose in the 1970s as a way for children and their families to escape the rigidity and severity of cancer treatment (Bluebond-Langner, Perkel, Goertzel, Nelson, & McGeary, 1990; Kids Cancer Care Foundation of Alberta, 2012). Cancer camps are designed to meet the needs of the whole family at each stage in the cancer experience—from diagnosis through treatment, to survival or bereavement (Kids Cancer Care Foundation of Alberta, 2012). In 2008, the eight camps across Canada provided specialized oncology camps and community support programs to 5,252 children and their families—a 10% increase from the previous 3 years (Canadian Association of Pediatric Oncology Camps, 2012). These cancer camps now exist throughout Canada, the United States, Australia, New Zealand and parts of Europe, and have pediatric oncology camping associations governing the camp experience. As more children are surviving childhood cancer, the need for specialized camps and community programs continues to grow (Canadian Association of Pediatric Oncology Camps, 2012).

**A case for why.** “It’s just camp – what is there to understand?” is a phrase (or variation on a phrase) I have heard several times throughout the course of this study. Presumably because of the fun nature of camp, some question the worthiness of engaging in such a project, as if there is nothing meaningful to understand. Many people, I came to realize, do not understand that kids with cancer are left out. Their suppressed immune systems (from chemotherapy and radiation) means they are highly susceptible to infection. An infection in a child with little to no immunity is a life-threatening event. Because of this risk, these children are unable to attend school for the majority of their treatment, cannot see their friends and engage in social activities with their peers, and
often miss out on significant events in their lives because of their disease. They also 
cannot attend regular summer camps (for healthy children), where children and 
adolescents engage in activities such as swimming, zip-lining, drama, and campfires. It 
is not untrue that cancer can rob a person of a childhood.

**Concluding Thoughts**

The interesting paradox of improved children’s cancer survival rates, coupled 
with a health care environment wrought with unprecedented financial constraints, speaks 
to the need for alternative ways of delivering health care. If children’s cancer camps 
were more fully understood, it is conceivable that they too could become viewed, or even 
targeted, as psychosocial interventions. Amylon (2010) echoed this sentiment, saying 
“what we do at camp is not only great fun for our campers, but also is an important part 
of their overall healing process on their cancer journey” (para.1).
Chapter Two: Review of the Literature

Many anecdotal accounts of the benefit of cancer camps exist, however a paucity of research has been conducted in this area. Before examining the literature related to these camps, it is important to take a step backwards, and look at the history and influences that have made camp what it is today. I have chosen to situate the topic of children’s cancer camps under the broader umbrella of outdoor education and adventure programming, given that these are undoubtedly the roots from where it began.

Outdoor Education and Adventure Programming

Since the 1950s, there has been a dramatic increase in outdoor education and adventure programs (hereafter called simply outdoor education), however the use of outdoor experiences for educational purposes has a long and rich history (Hattie, Marsh, Neill, & Richards, 1997). Plato claimed “(t)he moral value of exercises and sports far outweighed the physical value” (cited in Hattie et al., 1997, p. 43) and considered the aim of outdoor education being its educational value versus improved physical ability. A brief examination of the roots and influences of outdoor education will follow.

Early influences. Scholars have traced the origin of modern outdoor education to the (second) Industrial Revolution, and in particular to the creation of the factory (Landes, 2003; Stearns, 2007). Factories contributed to a rapid urbanization where many people left their rural homes seeking employment in cities. Landes (2003) reported that, among the changes associated with this urbanization, was a growing disconnect with nature. People had left their homes in the countryside where involvement in the outdoors was inescapable, to working inside factories, having little or no contact with the outside
environment. Norris (2009) identified several social movements that were happening concurrently that would have significant impact on the future of outdoor education:

…the rise of liberal notions of individual freedom and moral autonomy, as epitomized by Adam Smith’s philosophy which extolled individual moral and economic life as a backbone of social order (Denis, 1999); the influence of dissenting Protestant movements such as the Quakers, Baptists, and Methodists (Gilbert, 1993); a growing body of scientific ideas, such as Darwin’s theory of evolution, that increasingly challenged established religious truths and cultural certainties (Young, 1985); and a growing differentiation between spheres of social life that Habermas (1983) identified as the defining characteristic of modernity.

(p. 24)

**Early influencers.** Three movements have influenced the course of outdoor education: the Woodcraft movement; the Scouting movement; and, the Outward Bound movement (Norris, 2009). I have chosen to focus on the latter, the Outward Bound movement, as I believe it to be the most relevant to the topic of children’s cancer camps.

Modern adventure education is most often attributed to Kurt Hahn (Hattie et al., 1997). Hahn created the first Outward Bound program in 1941, consisting of a 4-week course designed to develop independence, initiative, fitness, self-reliance, and resourcefulness (Hahn, 1957). The success of this program led to the creation of Outward Bound schools, initially in England, then spreading throughout the world. Currently, there are approximately 40 Outward Bound schools in over 30 countries on six continents (Outward Bound International, 2007). The common features of Outward Bound programs include: wilderness or backcountry settings; small groups; mentally
and/or physically challenging tasks; frequent and intense interactions often requiring group problem solving and decision making; trained leaders; and, a duration of 2 to 4 weeks. Doing physically active things away from the person’s normal environment is the hallmark of Outward Bound.

**Research on outdoor education.** Hattie et al. (1997) performed a meta-analysis of outdoor education programs to examine their effects on outcomes such of self-concept, academic performance, leadership, interpersonal skills, personality, and adventuresomeness (defined by attributes such as openness to ideas, resourcefulness, challenge-seeking, etc.). They aimed to identify the outcomes most influenced by these programs, examine the differences between programs, and discuss the educational processes that led to the outcomes. Their meta-analysis was based on 1,728 effect sizes from 151 unique samples from 96 studies. Effect-size is the unit of measurement used in meta-analyses to indicate the existence and magnitude of a relationship between variables (Polit & Beck, 2008). While there was a wide variance in effect size between studies, the average effect size was .34. In other words, for the outcomes of leadership, academic, interpersonal, personality, adventuresomeness, and self-concept, an overall effect size of 0.34 is akin to: a 15% improvement in the rate of learning; a correlation between the outcome variable and participation in the program of 0.15; 65% of students participating in adventure programs exceeding those who do not; and a gain in outcome measure (with SD = 10) of approximately 3 points (Hattie et al., 1997).

The three individual variables the authors determined to have the most variance were age of the participant, length of program, and the country within which the program was held. Specifically, programs with adults (versus non-adults), longer duration (20
days or more) rather than shorter (less than 20 days) programs, and programs held in Australia (versus other countries) were determined to be the most effective individual variables across studies.

The authors pointed out that the effect size of .34 is not dissimilar to the effects of many classroom innovations, however there was a consensus across studies that the effects of these types of program are not easily quantified. There is something intangible that is garnered by participants of these programs that is not captured in measurement tools or expressed in numbers. In their recommendations for future research, Hattie et al. (1997) called for researchers to “consider alternative designs…(including) qualitative or grounded [sic] research designs” (p. 73) when studying outdoor education programs.

Hattie et al. (1997) suggested four premises relating to how outdoor education programs positively affect participants:

• Emphasize an immediate quality of experience, as well as aim to have these immediate experience impact future experiences;
• Set difficult and specific goals and structure tasks so that participants can attain these goals;
• Increase the amount and quality of feedback that is available to the participant throughout the experience;
• Provide opportunities for participants to reassess their coping strategies.

These items, they surmised, address the formative, or process aspects, of outdoor programs, and are likely to lead to positive changes in the participants.

**Models of change in outdoor education.** Priest (1999) offered that the goal of outdoor education is intentional change, and Norris (2009) identified (at minimum) one
dozen models of change currently being used. *Asset-building models* build on the strengths of the individual participants and boost resiliency by enhancing internal assets and protective factors. *Socially engaged models* utilize outdoor education to create social change by supporting broader mobilization and engagement initiatives, thus inducing social change. *Transpersonal models* cultivate spiritual qualities and encourage heightened states of awareness. *Wilderness therapy* uses outdoor education to support formal therapy and learning, bringing about changing beliefs and behaviors. *Ecotherapy* is healing in nature, wherein the participant engages with nature as a therapeutic modality. *Systems models* address systemic factors impacting individuals and change relationships within systems. *Ecopsychological models* encourage change through reconnection with nature, where the participant connects with their ecological self and bases subsequent actions on this experience. *Depth psychological models* utilize outdoor education to support healthy development and existential changes in participants. *Transition models* build on the idea of rites of passage, by catalyzing, marking, supporting, and ritualizing life transitions to find personal meaning. *Educational models* promote learning skills and knowledge through the medium of outdoor education. *Challenge models* develop character and leadership capacity through challenges. *Religious models* aim to deepen and expand the participants’ faith through experiences in nature, and *heritage models* promote connection and belonging to place, community, and culture.

**Research on children and nature.** Faber Taylor and Kuo (2006) performed a literature review examining whether contact with nature promotes healthy child development. The focus of their analysis was based on nature being defined in terms of
children’s contact with green spaces. A variety of forms of green spaces were considered, including wilderness programs, outdoor education programs with hands-on nature activities, and green space in neighborhoods, play settings and schools. The authors concluded that, despite recurring methodological weaknesses and different measures, research designs, and populations, the literature consistently points to a positive effect gained from children’s exposure to, and contact with, green spaces. Specifically, improvements in the sense of autonomy, self-concept and confidence, decisiveness, interpersonal skills, attentiveness and concentration, self-control, academic achievement, and overall well-being were all positively affected by interaction with green spaces, as defined above. The authors called for future research to not only address the (quantitative) methodological issues they identified, but to include qualitative research as well.

**Therapeutic camping literature.** Over the past few years, many childhood disease groups have organized camps for children specific to their disease (e.g., Camp Huff n’ Puff (asthma), Camp Maska (nephrology), etc.). There has been a substantial amount of literature and research pertaining to these therapeutic camps (e.g., Mishna, Michalski, & Cummings, 2001; Walker & Pearman, 2009; Welch, Carlson, Larson, & Fena, 2007), with most studies concluding that these camps are of benefit to the children for whom they are targeted. Childhood cancer, however, is a unique disease, and with that comes unique challenges, differences, and outcomes that must be considered with respect to camp. It is because of this that I have chosen to focus the remainder of my literature review on the therapeutic camping literature as it pertains specifically to children with cancer.
Children’s Cancer Camps

A literature search in nursing, education, family, and psychology databases yielded 16 studies (all under the umbrella of therapeutic camping) dealing specifically with cancer camps; in other words, very little is known or understood about the effects, or meaning, of cancer camps for the child and family. The earliest study, published in 1985 by Kessell, Resnick, and Blum, used pre/post testing and semi-structured interviews to examine the locus of control (Nowicki-Strickland Personal Reaction Survey), self-image (Offer Self-Image questionnaire for Adolescents), family environment (Moos Family Environment Scale), and family dynamics for adolescents with cancer and other chronic illnesses or disabilities, as well as able-bodied, healthy adolescents. Over a period of two years and within the setting of a wilderness Outward Bound program, data was collected for 31 individuals (18 were youth with chronic illness or disability, 13 were able-bodied, healthy adolescents). Results indicated a significant increase in internal locus of control for the disabled/chronically ill participants, however no change was noted for the able-bodied/healthy individuals. Body-image and social competence were both significantly improved (in both groups), and while changes in family environment showed significant decreases for family conflict, changes to family recreation patterns were unclear.

There were several limitations of this study. While the authors utilized valid tools of measurement for their outcomes of interest, they did not specify the breakdown of participants with cancer versus other chronic illnesses or disabilities. The small sample size and lack of randomization, while limitations not easily overcome for a study of this nature, need to be considered in the interpretation and generalizability of these results. Regardless, this study would appear to be the first foray into investigating the effects of a
summer camp experience on children with cancer, even though they are not the sole “type” of study participant.

Shortly after Kessell et al.’s (1985) study, Benson (1987) undertook what appears to be the first research project involving pediatric oncology children exclusively, and the effect of a summer camp experience. Specifically, she used a quasi-experimental design to determine the relationship between a summer camping program and self-concept of children who have cancer. Fourteen participants ranging in age from 7 to 18 years completed the Piers-Harris Children’s Self-Concept Scale and a modified version of the Kinetic Family Drawings Scale. Both measures were completed pre and post-camp, and while there was no significant increase found in self-concept, the results of the pre/post camp drawings were significant in the areas of self-image and emotional tone. Limitations in the study include small sample size, lack of control group and randomization, and pre/post testing timeframes were not specified.

I offer a comment on limitations: without exception, each of the studies that have been conducted in this area have either self-identified or been criticized by other researchers as having limitations involving small sample size, lack of randomized sampling, and no external control group (there were other limitations as well, however these are the ones common to all studies). While these limitations are of concern in quantitative research, it bears noting that they are not easily overcome due to the fact that it is unethical to randomly assign some children with cancer to attend camp while others are randomly assigned not to attend. Random selection therefore, in these situations, cannot ethically occur. Secondly, the pediatric oncology population simply does not exist in numbers high enough to give power to quantitative studies. The only conceivable way
to attain a sample size large enough for power to be achieved is by conducting a multi-site study. Given that pediatric cancer camps operate differently, each with their own vision, mission, and mandate, this would require an enormous amount of operational and financial resources. It is unlikely that a study of this magnitude will be undertaken. It can be assumed that all subsequent studies hold the limitations mentioned above, therefore to avoid repetition I will only mention pertinent limitations in addition to the ones already named.

Smith, Gotlieb, Gurwitch, and Blotcky (1987) studied the impact of summer camp on the daily activity and family interactions for children with cancer and their siblings. Eighteen pediatric cancer patients and their families completed questionnaires at three different time intervals: 2-weeks prior to camp, 2-weeks after camp, and 1-month after camp. The Interaction with Environment Checklist and the Daily Activity Scale were used to measure the amount of time the child spent in physical, social, and independent activities. All outcome measures were shown to increase, and, with the exception of physical activity, these improvements were maintained at the 1-month post camp interval. Similarly, interactions with others (including the child’s family) increased post-camp. The researchers surmised that the data from this study “support the use of a camp experience as an intervention to facilitate a return to more normal, healthy functioning by pediatric cancer patients and their families” (Smith et al., 1987, p. 533). The authors noted that limitations to their study include the lack of standardization of the Daily Activity Scale, in addition the ones I have mentioned above.

Chronologically, the next study involved siblings of children with cancer. Carpenter, Sahler, and Davis (1990) examined the effect of a camping program
specifically designed to provide medical information to siblings of children with cancer. Ninety siblings between the ages of 6 and 17 completed a pre/post camp medical information questionnaire to ascertain their level of comprehension around their sibling’s illness. The results indicated that younger siblings (6 to 11) attending camp for at least the second time, and older siblings (12 to 17) attending camp for the first time, experienced significant improvement in their overall comprehension about (childhood) cancer, concurrent with a measurable decrease in the fear they held about the disease. The changes noted were sustained at the 3-month post camp interval, however the researchers reported that only 65% of participants completed the questionnaire at that time. Because of the positive results of this study, the authors recommended camps implement programs designed specifically for siblings of children with cancer.

The Carpenter et al. (1990) study was the first study designed specifically for the siblings of pediatric oncology patients. This coincides with the early 1990s being when siblings of children with chronic illnesses were noted in the literature to be (often) the most impacted of family members, yet the least attended to (Bendor, 1990; Cadman, Boyle, & Offord, 1988; Kinrade, 1985; Rollins, 1990; Sharpe & Rossiter, 2002; Spinetta & Deasy-Spinetta, 1981; Wood et al., 1988). From this point in time, there are many more studies in the therapeutic camping literature that pertain to siblings of children with cancer.

Bluebond-Langner et al. (1990) examined whether cancer and treatment were informally discussed by pediatric oncology patients at camp. Additionally, the kind of information, and how these interactions affected children’s understanding of their disease and treatment, were of interest. Data collection from the 50 participants included open
ended, structured interviews 1-month before and 6-months after camp, as well as parent questionnaires before and after camp. Observational accounts of the campers before, during, and after camp were used to supplement the data obtained from the interviews. Results indicated that children do engage in informal discussion about cancer and its treatment, showing a significant increase in their knowledge of cancer and its treatment after camp, despite the lack of formal instruction. The researchers concluded that attending camp, for children with cancer, improves their knowledge of the disease and its treatment, and that it is unnecessary for camps to provide a formalized program of delivering medical knowledge.

From the same study, Bluebond-Langner et al. (1990) published another paper with a second area of analysis in 1991. In this second paper, they investigated the peer relationships that were developed among the campers during their summer camp experience. Interviews were used in this case study, quasi-experimental design, to assess children’s views of camp, their relationships with their peers, and the impact of camp on these outcomes. Results indicated 26% of the children considered the friends made at camp to be among their “best” friends, and 54% of children stayed in touch with their camp friends throughout the year. Data obtained through post-camp questionnaires ascertained that camp friends were considered a source of empathy (32%), understanding (20%), and to a lesser degree, acceptance (8%), and hope (3%). Children acknowledged that there were disadvantages to having friends with cancer, such as fear of offending, increased concern for their own health status, and fear of losing a friend to relapse and death. The authors surmised, “although the relationships that the children form at camp are extremely important to them, they do not replace their relationships with healthy
peers. Each type of relationship fulfills different functions” (Bluebond-Langner et al., 1991, p. 68).

Interestingly, after Bluebond-Langner et al.’s (1990, 1991) publications, the early 1990s were a dormant period for research around children’s cancer camps. A 6-year gap exists until the next study, conducted by Ruffin, Creed, and Jarvis (1997), wherein the family with the child with cancer was the focus of investigation, versus only the child with cancer and/or his or her sibling. Ruffin et al. investigated a family retreat program developed in response to a comprehensive needs assessment done for families of children recently diagnosed with cancer in Columbia, South Carolina. Using a 19-item questionnaire developed to ascertain if the family weekend retreat met the families’ needs for education, recreation, and mutual support, all questionnaire items indicated increases in a positive direction, with the most positive responses given for questions regarding mutual support between families. The authors concluded that this type of intervention might be useful to provide a network of support among families of recently diagnosed children who struggle through the cancer experience. While some might question the applicability of this article, particularly whether a program evaluation can be considered in the same way as a research study, I have included this article for two reasons: first, the paucity of research conducted in this field makes me inclined to “broaden my consideration” of what will and will not be reviewed; second, this is the first study to consider the family as the subject of consideration. Given that it is widely accepted that when a child is diagnosed with cancer the entire family is affected (Packman, 1999; Scott-Findlay & Chalmers, 2001; Woodgate, 2006), this is an important point to mark in the history of cancer camp research.
The late 1990s saw the reemergence of research related to cancer camps for pediatric oncology patients and families. Balen, Fielding, and Lewis (1998) investigated the factors discriminating between families who send their children to cancer camps versus families who do not. They sought to understand the factors that families consider when making the decision to send, or not to send, their child to camp, what fears they had, and to assess whether the week at cancer camp had a significant effect on the self-concept of the participants. Parents of children with cancer were sent a questionnaire which included demographic items, Likert-type scales for factors considered when deciding to apply to send their child to cancer camps, and for rating how family members felt about the idea, along with who had been the most influential in reaching the final decision. Of the 220 questionnaires mailed, 135 were returned to the researchers. Findings showed that the week at camp appealed to individuals who are confident, active, and able to separate from their parents, and whose parents placed value on their children’s independence and new experiences. For families who chose not to send their child to camp, homesickness and the child’s wish were the factors most strongly considered.

Researchers then turned their attention toward the effects on the sibling of the child with cancer. Perhaps heeding the call of Carpenter et al. (1990) who drew attention to how understudied these siblings were, the early 2000s saw a (relative) proliferation in research examining the effects on the sibling of the child with cancer. In 2001, Murray investigated the self-concept in siblings of children with cancer who attended summer camp. This descriptive design study had 50 participants consisting of school-aged siblings of children with cancer. Of these 50 participants, 22 (44%) had attended summer
camp and 28 had not (56%). The Personal Attribute Inventory for Children was used to measure self-concept, and the findings of the study showed that self-concept was higher in the children who had attended camp versus those who had not. While it is unclear whether factors other than camp might have contributed to this finding, Murray surmised that social support, such as a camp experience, might play an important role in coping with having a brother or sister with cancer. Had the researcher measured self-concept pre/post camp, it would be easier to concur with this assumption. Given that there may be intrinsic factors already present in the siblings who chose to attend camp in the first place (e.g., their self-concept may already have been high) it is difficult to agree with the conclusions drawn by the researcher, even though it might “make sense,” intuitively, that camp would have a positive affect on the self concept of a sibling of a child with cancer.

In 2005, Packman published the first of two articles based on the same study, but with different outcomes investigated in each (her co-authors changed with each study). The following two studies took place at a summer camp for siblings of children with cancer. For clarity, I will discuss these two articles sequentially, even though it takes this literature review out of chronological order for this section. This camp was designed to address emotional problems, provide peer interaction and validation, and improve self-esteem. In the first study by Packman et al. (2005), quantitative and qualitative methods were used to assess the pediatric health-related quality of life in the same cohort of siblings (n = 77) described above. The purpose for the study was to advance the understanding of quality of life in siblings of pediatric cancer patients. Quantitative measures included the Pediatric Quality of Life Inventory (PedsQL - parent and child versions), and qualitative measures included a grounded theory approach to “complement
the PedsQL results and provide a more in-depth meaning of the effects of camp on health-related quality of life (HRQL)” (Packman et al., 2005, p. 97). From the quantitative perspective, results indicated that all siblings reported statistically significant improvements in HRQL following camp (p = 0.001). Parents (when controlled for non-bereaved responses) also reported significant improvements in siblings HRQL following camp. From the qualitative perspective, six psychosocial themes were identified reflecting the siblings’ positive emotional and social experiences at camp: group cohesiveness, development of socializing techniques, universality, instillation of hope, interpersonal learning, and catharsis. On the basis of both qualitative and quantitative findings, the authors suggested that camp is a useful psychological intervention for siblings of children with cancer.

In the second article coming from this study, Packman et al. (2008) administered standardized tests to 77 siblings prior to attending camp, and 3-months after camp. The researchers were interested in psychosocial functioning, particularly related to emotional distress (Human Figure Drawing) and family environment (Kinetic Family Drawing-Revised). From pre to post camp, result indicated significant decreases in symptoms of emotional distress (p < 0.001) and improvement in family environment (p < 0.001). The authors suggested that the encouraging findings of the research indicate the value of the summer camp experience as a psychosocial intervention for siblings of children with cancer.

Sidhu, Passmore, and Baker (2006) examined the effectiveness of a peer support camp for siblings of children with cancer. Specifically, the purpose of this study was to determine the effectiveness of a camp for siblings of children with cancer, as a health
promoting intervention. Twenty-six siblings were assessed using standardized self-report measures pre, immediately post, and again at 8-weeks post their camp experience. Anxiety and social competence (the Self-Report of Personality), scholastic and athletic competence, social acceptance, physical appearance, self-worth (Self-Perception Profile for Children), and the impact of their siblings’ illness (Sibling Perception Questionnaire) were measured. Results of these measures demonstrated improved mental health outcomes for siblings from pre to post camp that were sustained at the 8-week post camp interval, demonstrating the effectiveness of camp as an intervention for supporting siblings of children with cancer.

Keeping with the apparent trend of studying siblings, Wellisch, Crater, Wiley, Belin, and Weinstein (2006) reported on how the camp experience impacts mood, social interactions, and relationships with children and adults in pediatric cancer patients and their siblings. Additionally, the authors sought to determine what activities these children participated in, and their reaction to a variety of camp activities. Using a pre/post test design, 31 patients and 35 siblings (n = 66) underwent standardized testing for depression (Children’s Depression Inventory (CDI)), social competency (Youth Self-Report), and pleasure in camp activities (Things You Did at Camp). Results of the study showed significant improvement in CDI at follow-up time 2 (4-6 months after camp) for the children with cancer, but there were no statistically significant improvements noted for the siblings. The disparity in results between patients and siblings highlighted that the camping experience impacts each group differently, and what may been seen as therapeutic and life changing for one group (e.g., patients) may be experienced very differently for another group (e.g., siblings). The results of this study suggested that
patients and siblings have different psychosocial needs requiring different levels of interventions.

Conrad and Altmaier (2009) assessed the types of social support received by children with cancer who attended summer camp. Specifically, they sought to “expand the research on social support and adjustment in children with cancer by exploring the types of support these children attain while attending summer camp” (Conrad & Altmaier, 2009, p. 151). Questionnaires and camp evaluations were sent to families 2-weeks following camp. Parents were asked to fill out a behavior checklist (The Child Behavior Checklist) pertaining to behavior in their child since camp. Campers were asked to complete a social support measure (the Survey of Children’s Social Support) related to their experience at camp. Of the 26 families that responded (representing a return rate of 25%), females received more social support than males, however, both females and males reported receiving more social support within the camp setting than in their regular lives. Parental reports on their child’s behavior showed no significant difference from a comparable clinical sample. Of note, the authors did not describe what kind of “comparable clinical sample” (Conrad & Altmaier, 2009, p. 155) they compared their findings with, and given that this was a post test only (versus pre/post test), it is impossible to (quantitatively) conclude that camp had any effect on the children.

In 2010, Barr et al. published a study entitled, “A comparative assessment of attendance and nonattendance at Camp Trillium by children with cancer and their families; including their utilization of health and social services.” As the title implies, the purpose of their research was to assess the effects of camp attendance on family members, including utilization of health and social services. A random sample of camp
attendees (selected from a database) was paired with a randomized, matched sample of camp non-attendees. Following a historical cohort analytic design, parents from each group completed measures on family functioning (The McMaster Family Assessment Device), health-related quality of life (HRQOL), child’s behavior and relationships (National Longitudinal Survey of Children and Youth (NLSCY)), parenting and depression (NLSCY Parent Questionnaire), parental coping (The Indices of Coping), and parental social support (NLSCY Parent Questionnaire). To measure and compare service utilization between group, parents were also asked to complete the Health and Social Service Utilization Inventory. Parents of camp attendees reported significantly better family functioning (p = 0.017), social support (p = 0.014), parenting coping (p = 0.006), and consistent parental behavior (p = 0.0001) than parents of the non-attendees. Health service utilization was also significantly higher among families of children who attended camp. This finding is consistent with assertiveness and problem-solving abilities found in parents of the attendee group. The authors concluded that, given this was a retrospective randomization and that it is not ethically possible to prospectively randomize children to attend camp, it cannot be determined if better-adjusted families send their children to camp, or if camp attendance improves the health and welfare of families and children with cancer. Regardless, they report the need for greater efforts to promote the camping experience, and for health care professionals to encourage children and families to participate.

Most recently, Wu, Prout, Roberts, Parikshak, and Amylon (2010) examined the experiences of children with cancer, and their siblings, who attended camp. Eighty-nine families with children with cancer completed the Camp Evaluation Survey for
Campers/Parents (a mail-based survey), assessing satisfaction with recreation, peer support, and camp features. The results indicated that families were highly satisfied with the camp experience, and that they perceived camp to be useful and enjoyable for their children for many reasons (peer support, respite, behavioral improvements). Campers reported being highly satisfied with camp as well, due to peer support, respite from home/hospital life, and recreational opportunities.

The authors acknowledged several limitations of their study. First, this was a non-standardized questionnaire thus results may not be generalizable to other camps. Second, minorities were not represented in the participants, and third, families with more positive experiences may have been more willing to participate in this study.

To summarize, of the 16 research studies that have been published to date, seven pertained to the child with cancer (Balen et al., 1998; Benson, 1987; Bluebond-Langner et al., 1990; Bluebond-Langner et al., 1991; Conrad & Altmaier, 2009; Kessell et al., 1985; Smith et al., 1987); five studies examined the sibling (Carpenter, et al. 1990; Murray, 2001; Packman et al., 2005; Packman et al., 2008; Sidhu et al., 2006); and two studies looked at the sibling and child with cancer together (Wellisch et al., 2006; Wu et al., 2010). With respect to the constructs that were measured, two studies examined the effect of camp on the family (Barr et al., 2010; Ruffin et al., 1997); three studies examined self-concept (Benson, 1987; Kessell et al., 1985; Murray, 2001); three looked at support received at camp (Bluebond-Langer et al., 1991; Conrad & Altmaier, 2009; Sidhu et al., 2006); two at psychosocial impact (Packman et al., 2008; Wellisch et al., 2006); and two studies examined medical knowledge gained from camp (Bluebond-Langner et al., 1990; Carpenter et al., 1990). Four of the studies were done in the 1980s,
five in the 1990s, and six studies were done from 2000-2009. Since 2010, two studies have been published in this field, and it is difficult to predict whether this slow but steady increase will continue. The common thread among these 16 studies is that, despite methodological challenges or construct examined, cancer camps are of benefit to the child with cancer and/or his or her family.

**What Has Yet to be Discovered?**

Be it in outdoor education, adventure programming, or children’s cancer camps, the existing research is predominantly from the quantitative paradigm. Constructs such as self-concept, support, and psychosocial impact will always lend themselves well to psychometric measurements, and undoubtedly will continue to be the foci of future quantitative researchers. Interestingly though, much of the literature reviewed spoke to the limitations of these measures; how “something was missing,” or at the very least, inadequately capturing the data. In some of the articles, the tone of the discussion or conclusion sections had an element of frustration to it – as if the researchers knew there was more there, but were limited by way of method.

There is much to be learned from children’s cancer camps, starting with the most fundamental of concepts: how might we understand the meaning of children's cancer camps for children and their families? I believe what is missing from the current literature is the voice of the children and their families. What do they think? What do they have to say? What can they teach us? There is richness and complexity in the experience of cancer camps that has not, as yet, been captured by the existing research. There is, as Hattie et al. (1997) suggested, an “intangibleness” to camps that may lend well to qualitative research approaches. This complexity is difficult to access by
quantitative means alone and, to the best of my knowledge, this is the first hermeneutic study related to children’s cancer camps. Hermeneutic inquiry, as the following chapter will detail, is well situated to make sense of some of the particulars and complexities of children’s cancer camps. While quantitative approaches are useful in many instances, any single approach to understanding is limited, and many authors have argued that qualitative research can provide answers to questions that no quantitative approach could address (Koch, 1996; Moules, 2002; Smits, 1997).
Chapter Three: Hermeneutics as Philosophy and Research

Hermeneutics is a term that covers many different levels of reflection, as is frequently the case with Greek words that have become part of the terminology in our scholarly disciplines. Hermeneutics refers, first of all, to a practice, an art, that requires a special skill...Hermeneutics is the practical art, that is a techne, involved in such things as preaching, interpreting other languages, explaining and explicating texts, and, as the basis of all of these, the art of understanding, an art particularly required any time the meaning of something is not clear and unambiguous. (Gadamer, 1977, p. 44)

Hermeneutics as Philosophy

Hermeneutics dates to 17th century biblical and theological textual interpretation and begins with the assumption that the world is interpretable (Moules, 2002). It is defined as the art and practice of interpretation (Gadamer, 1960/1989), and has been used throughout history from religion to academia to interpret text and bring forth meaning. Gadamer (1996) offered that hermeneutics is a theoretical attitude toward the practice of interpretation, and to the way experiences in text are interpreted.

The word hermeneutics is from the Greek word hermeneia, meaning bringing understanding to particulars, where the process involves language (Collins English Dictionary, 2012). Etymologically, it is related to Hermes who was the son of Zeus and younger brother to Apollo (Online Etymology Dictionary, 2012). Hermes is given many titles in Greek mythology, but his general role was said to be as messenger from the gods to humans (Palmer, 1999). When it came to delivering messages from deities to humans, Hermes needed to bridge an ontological gap as there were differences in the ways of
thinking between gods and humans (Palmer, 1999). In order to make the gods’ messages understood (in order to bridge the gap), Hermes needed to translate. He is also said to have been a trickster, magician, thief, and the transporter of the dead to the underworld. In this sense, he crossed the boundary of life and death, and so also he is the god of crossroads and boundaries (Palmer, 1999). This precedence over the worlds of Earth (life) and Hades (death) speaks to a central component in hermeneutics – mediation between worlds (Palmer, 1999).

Throughout history, hermeneutics has been used to interpret text and bring forth meaning. The heart of hermeneutics is to respond to the question, how is understanding possible? (Gadamer, 1960/1989). Hermeneutics offers a way to know and understand the world and thus, the topic. It is an interpretive methodology, which expects knowledge to emerge from dialogue in the form of an unpredictable discovery rather than a controlled outcome (Annells, 1996). It is a reflexive inquiry where the researcher is not considered a separate entity, a non-influencing factor, from that which he or she is researching. “Hermeneutics is not founded upon the separation of researchers from the earthly life they live or the lives that are the topics of their research” (Jardine, 2000, p. 105).

A Brief Historical Tracing

Hermeneutics, as a philosophy, practice, and method, has been influenced and shaped by numerous philosophers over hundreds of years. Detailed historical tracings exist, outlining the nuances of hermeneutics’ evolution (e.g., Odman, 1988; Palmer, 1969), however I offer only a brief account of some of the influential hermeneutic scholars.
Friedrich Schleiermacher (1768-1834). Friedrich Schleiermacher, professor of theology and translator of Plato, defined hermeneutics as the theory of understanding (Grondin, 1994). He stated, “every act of understanding is the inverse of an act of speech” (Gadamer, 1960/1989, pp. 188-189), and maintained that the task of hermeneutics was one of reconstruction. In order for understanding to be achieved, the interpreter must be able to reconstruct the meaning of the author with the imperative of “understanding the author better than he understood himself” (cited in Grondin, 1994, p. 71).

Until Schleiermacher, traditional hermeneutics maintained that people generally understood concepts quickly and easily, and hermeneutics was useful only when understanding was not obvious (Grondin, 1999/2003). Schleiermacher argued that it is, in fact, misunderstanding that is the normal state, and the interpreter must be constantly vigilant against misunderstandings (Grondin, 1994). He advocated for a wider application of hermeneutics and offered several differentiations in his contributions to hermeneutics, the first between the grammatical and technical side of interpretation. The grammatical side of interpretation, he maintained, focuses on language and the prescribed syntax, flow, and pattern of usage inherent within; in other words, the structure of language. The technical side (later called the psychological side) focuses on the meaning the interpreter is trying to bring to the text. Schleiermacher also distinguished between a stricter and laxer practice of interpretation (Grondin, 1994). The laxer practice of interpretation is concerned with the avoidance of misunderstanding, while the stricter practice of interpretation begins with the fact that understanding must be sought at every point. Schleiermacher’s hermeneutics encouraged this stricter practice of interpretation.
Schleiermacher’s insistence that misunderstanding is always the starting point of interpretation can be extended to the idea that, despite every attempt at understanding, the possibility of misunderstanding can never be ruled out. He was first to introduce the concept of the hermeneutic circle by noting the circular pattern of understanding from parts and wholes, however Schleiermacher intended it as a description of the process of understanding versus a fundamental principle (Gadamer, 1960/1989). He also stressed the importance of creativity as well as the pivotal role of language in interpretation (Smith, 1991).

**Wilhelm Dilthey (1833-1911).** Dilthey was a German philosopher who was best known for the way he distinguished between the natural and human sciences. He is credited as being the first to attempt to appropriate hermeneutics for the human sciences (Todres & Wheeler, 2001), and was concerned with preserving the autonomy of the human sciences (Grondin, 1999/2003). Dilthey proposed a separate model for understanding the human sciences based in human consciousness in order to elevate and legitimize the human sciences from the empirical study of the natural sciences (Grondin, 1994). His argument centered around the idea that the natural sciences seek to explain phenomena in terms of cause and effect, while the human sciences seek to understand in terms of the relations of the part and the whole (Grondin, 1994).

Dilthey saw understanding as a dialogue in which interpretation always occurs with reference to a personal, shared, and historical position (Todres & Wheeler, 2001). In this sense, he believed that understanding is always situated and never absolute. Hermeneutics, for Dilthey, represented a general methodology he hoped would become the theoretical foundation for all the humanities and social sciences (Palmer, 1999).
Further, Dilthey suggested that written language is a superior form of communication (Moules, 2002) and claimed that the role of the interpreter, when interpreting text, is to uncover the original intention of the author.

Gadamer (1960/1989) was critical of Dilthey’s approach to hermeneutics, accusing it of being overly method-oriented and in imitation of the natural sciences. According to Gadamer, Dilthey was insufficiently concerned with the ontological event of truth, and did not consider how the interpreter and his or her interpretations are not outside of tradition, but occupy a position within it.

**Edmund Husserl (1859-1938).** Husserl is referred to as the father of phenomenology and introduced the concept of the “life-world” (Cohen, 1987; Koch, 1996; Polkinghorne, 1983; Scruton, 1995). The life world, according to Husserl (1970), refers to what we experience pre-reflectively, without resorting to categorization or conceptualization, and often includes what is taken for granted, or those things considered common sense (cited in Laverty, 2003). Phenomenology, then, re-examines these taken for granted experiences, perhaps uncovering new or forgotten meanings (Laverty, 2003). It is the study of phenomena, and seeks to understand and describe the lived experience (van Manen, 1990). The aim of phenomenology is to describe the essence of a phenomenon – the “thing” without which it would not exist (Dowling, 2007).

Husserl’s primary focus was the study of phenomena as they appeared through consciousness (Laverty, 2003). As a mathematician as well as a philosopher, he was concerned with how methods of the natural sciences overshadowed the experiential nature of the human sciences (Laverty, 2003; Todres & Wheeler, 2001). He understood
phenomenology as a scientific method in which human consciousness can discover the essence of a phenomenon by bracketing, or setting aside, our own prior knowledge of the phenomenon (Grondin, 1999/2003). Husserl believed that one needed to bracket out the outer world, as well as one’s own biases, in order to reach the essence of a phenomenon (Laverty, 2003), and achieve understanding. Husserl viewed intentionality and essences as key to our understanding of phenomenology (Koch, 1995). Intentionality is a process where the mind is directed toward objects of study creating the starting point in building one’s knowledge of reality (Laverty, 2003). “By intentionally directing one’s focus, Husserl proposed one could develop a description of particular realities. This process is one of coming face to face with the ultimate structures of consciousness” (Laverty, 2003, p. 5). These structures were described as essences that made the object identifiable as a particular type of object or experience, unique from others (Edie, 1987). He claimed that experience is the source of all knowledge.

**Hermeneutic phenomenology and phenomenology.** Hermeneutic phenomenology and phenomenology are often used interchangeably without noting the distinction between them (Laverty, 2003). Hermeneutic phenomenology is similar to phenomenology, however, instead of merely describing a phenomenon, researchers seek to interpret the phenomenon (Laverty, 2003). Heidegger (1927/1962) claimed that pre-understanding is not something that can be put aside or stepped out of, therefore within the tradition of hermeneutic phenomenology, bracketing does not (cannot) occur.

While hermeneutic phenomenology does not offer a prescribed method of conducting research, several authors have endeavored to systematize this process (Colaizzi, 1978; Giorgi, 1985; van Manen, 1990). van Manen’s (1990) method involves
six defined steps, starting with turning to a phenomenon of interest to the researcher, and concluding with balancing the research context by considering parts and wholes. van Manen said that hermeneutic phenomenology should be attentive to both terms of its methodology: it is descriptive (phenomenological) and it is interpretive (hermeneutic).

**Martin Heidegger (1889 – 1976).** Martin Heidegger was a student of the phenomenologist Edmund Husserl. Heidegger (1927/1962) rejected the notion of “bracketing,” and sought to understand what we are and answer the question of “Being.” His concept of Being (*Dasein*) has no English translation, however it is often referred to as existence, or a situated-ness in the world, characterized by the capacity for self-reflection about its own existence (Moules, 2002). This concept speaks to the person and the world being co-constituted and, as such, people make sense of the world from within their existence verses being detached from it (Koch, 1996). According to Bauman (1978), the central message of Heidegger is that existence is its own disclosure (as cited in Annells, 1996). Heidegger believed that life was not a phenomenon requiring explanation, rather it is something which is “revealing and concealing, coming and going, present and absent – and the work of hermeneutics is entering into the interpretation of these things” (Moules, 2002, p. 15). Heidegger suggested that the world is tacitly intelligible to us.

Heidegger is credited with making an ontologic shift in hermeneutics by questioning the notion of *Dasein*. He viewed humans as being primarily concerned creatures with an emphasis on their fate in an alien world (Annells, 1996; Jones, 1975). He recognized people as being situated in, and constituted by, their worlds (Moules, 2002) and, according to Heidegger (1927/1962), hermeneutics is ontological; it is about
the fundamental conditions of human’s being in the world. Some would say that
Heidegger’s magnum opus, *Being and Time*, turned metaphysics “on its head” and
transformed hermeneutics.

In Heidegger's view, hermeneutics is not a matter of understanding linguistic
communication. Nor is it about providing a methodological basis for the human
sciences. Understanding, in Heidegger's account, is neither a method of reading
nor the outcome of a willed and carefully conducted procedure of critical
reflection. It is not something we consciously do or fail to do, but something we
are. Understanding is a mode of being, and as such it is characteristic of human
being, of *Dasein*. The pre-reflective way in which *Dasein* inhabits the world is
itself of a hermeneutic nature. Our understanding of the world presupposes a kind
of pragmatic know-how that is revealed through the way in which we, without
theoretical considerations, orient ourselves in the world. (Malpas, 2009, para. 28)

**Hans-Georg Gadamer (1900 – 2002).** Hans-Georg Gadamer was a student of
Heidegger, and furthered Heidegger’s work around pre-understandings, historicity,
dialogue, the hermeneutic circle, and the theory of horizons while also attending to the
importance of the researcher and the linguisticity of understanding (Annells, 1996).
Gadamer is said to have revived hermeneutics in response to the Cartesian, positivist
paradigm dominating the natural sciences at the time (Grondin, 1999/2003). Like his
predecessors, he believed that the human sciences utilized knowledge that was not
understandable through the methods of the natural sciences. Gadamer did not attempt to
refute the usefulness of the natural sciences paradigm; instead, he argued against the
dominant discourse of it being the only useful, or legitimate, form of knowledge.
A major assumption of Gadamer’s hermeneutics (often called philosophical hermeneutics, although one could argue that all hermeneutics is philosophical) is that understanding and interpretation cannot be separated. “Understanding is always interpretation, and hence interpretation is the explicit form of understanding” (Gadamer, 1960/1989, p. 307). Hermeneutic inquiry attempts to express how things already exist in the world, how it is to be in the world and of the world (Grondin, 1999/2003). Gadamer argued that to be human is to have one’s being in language. One experiences the world through language, and we cannot understand ourselves unless we understand ourselves as situated in a linguistically mediated, historical culture. To Gadamer, language is the fundamental mode of operation of our being-in-the world. The understanding of transmitted messages and language are not two processes, but one and the same. Just as we can we never know a historical work as it originally appeared and was intended, understanding does not imply knowing what the author “meant.”

To understand a text is to come to understand oneself in a kind of dialogue. This contention is confirmed by the fact that the dealing with a text yields understanding only when what is said in the text begins to find expression in the interpreter’s own language. Interpretation belongs to the essential unity of understanding. (Gadamer, 1960/1989, p. 57)

According to Grondin (1999/2003), Gadamer is considered one of the most influential philosophers of the 20th century. Gadamer details in his magnum opus, Truth and Method, his understanding of philosophical hermeneutics. He expanded on Heidegger’s (and others’) work to present an integrated hermeneutic approach to the nature of human understanding (Grondin, 1999/2003). Gadamer was critical of Dilthey’s
ideas and, in some ways, *Truth and Method* can be understood as a reply to Dilthey (Grondin, 1999/2003). Particularly, Gadamer disagreed with Dilthey’s notion that the task of interpreting text was to uncover the original meaning of the author (a carryover from Schleiermacher). Interpretation of text, he claimed, involved a fusion of the horizon of the interpreter with that of the text to create new understanding.

**Prejudice.** “Have the courage to make use of your own understanding” (Kant, 1784, cited in Gadamer, 1960/1989, p. 271). Gadamer made great efforts to extract the word “prejudice” from its negative connotations. He defined prejudice as “a judgment that is rendered before all the elements that determine a situation have been finally examined” (Gadamer, 1960/1989, p. 270), and noted that it was not until the Enlightenment that the word acquired the negativity associated with it today. Prejudices are formed from one’s experiences and history. In this sense, prejudice refers to the fore-structures of understanding that allow what is to be interpreted to be understood in a preliminary fashion (Malpas, 2009); they represent the starting point of understanding (Maggs-Rapport, 2001; Smith, 1991). Gadamer insisted that all understanding occurs in light of our prejudices (Grondin, 1999/2003).

Gadamer disagreed with Heidegger around the concept of the fore-structures, or prejudices, of the interpreter, and the role that they have in understanding. Heidegger insisted that one’s fore-structures or pre-understandings, as he termed them, should not be considered with interpretations. He wrote:

> In the circle is hidden a positive possibility of the most primordial kind of knowing, and we genuinely grasp this possibility only when we have understood that our first, last, and constant task in interpreting is never to allow our fore-
having, fore-sight, and fore-conception to be presented to us by fancies and popular conceptions, but rather to make the scientific theme secure by working out these fore-structures in terms of the things themselves. (Heidegger, 1927/1962, p. 153)

Heidegger suggested that all interpretations should be guarded against “arbitrary fancies and the limitations imposed by imperceptible habits of thought” (cited in Gadamer, 1960/1989, p. 266), and that the interpretive lens one uses must be cast “on the things themselves” (Gadamer, 1960/1989, p. 267), a term he inherited from Husserl.

Gadamer (1960/1989) offered that it is impossible to completely separate oneself from one’s prejudices. In research guided by philosophical hermeneutics, the researcher is not separate from the phenomena he or she seeks to understand. We do not suspend our prejudices prior to engaging with our topic (Jardine, 2000); rather, hermeneutic inquiry encourages researchers to reflect upon their own prejudices as this will allow them to move beyond them and into understanding the phenomenon (Fleming, Gaidys, & Robb, 2003). In spite of this deliberate attempt to engage one’s prejudices, it is always acknowledged that we are not necessarily aware of all of our prejudices, in fact “we are most influenced by the ones we have no idea we possess” (Moules, 2002, p. 25). Unlike phenomenology, for example, the researcher does not bracket, or set aside, any antecedent knowledge, ideas, or opinions on the topic, but rather recognizes the influences, experience, and history that make up these prejudices, using them to uncover meaning and offer new interpretations or truths. Moules (2002) offered that it is our prejudices that allow us to understand the topic in ways we would not have been able to
otherwise. So essential are our prejudices to understanding, that Gadamer insisted understanding is not possible without them.

It is difficult to delve deeper into the concept of prejudice without consideration of historical consciousness, for I believe they are intimately related. Historical consciousness refers to the fact that we live in a world of tradition, of “always, already.” “We are always, already affected by history. It determines in advance both what seems to us worth inquiring about and what will appear as an object of investigation” (Gadamer, 1960/1989, p. 300). Things, as it were, have always already existed before we came to know of them, and we are inextricably linked to our past. We are our history, and understanding always occurs within the context of our history. Moules (2002) explained:

We are connected in a continuous thread with our past, with traditions, and with our ancestors. We are living out traditions that have been bequeathed to us by others, and although we may be taking them up in different ways, they are still the source of who we are and how we shape and live our lives. The echoes of history are always inadvertently and deliberately inviting us into both past and new ways of being in the present. We live in a world that recedes into the past and extends into the future, rather than pitting ourselves against history, and therefore we need to remember, recollect, and recall it. This is not an epistemological quest but an ontological one as we are historical. The address of tradition is not just something arching from before, for we are in tradition. (p. 2)

Gadamer suggested that understanding occurs within a context of historical consciousness. He advocated for a reflexive awareness of historicity, as there is no escaping our history or prejudices (Grondin, 1999/2003). They are the prerequisite for
understanding to occur in the first place, and are always already there (Palmer, 1969).

Moules (2002) offered that one cannot shed prejudices, rather there is an acknowledgement that our prejudices, whether we are aware of them or not, are always at play and influence in all we interpret.

A person who believes he is free of prejudices, relying on the objectivity of his procedures and denying that he is himself conditioned by historical circumstances, experiences the power of the prejudices that unconsciously dominate him...A person who does not admit that he is dominated by prejudices will fail to see what manifests itself by their light. (Gadamer, 1960/1989, p. 360)

**The hermeneutic circle.** Occasionally, the complexity and beauty of a piece of art is best appreciated by looking at it in parts, then stepping back and looking at the whole, then looking at another part and stepping back once again to look at the whole. This type of understanding occurs not just with art but also with text. The hermeneutic circle is a metaphor for understanding, and refers to the way of understanding text hermeneutically. It refers to understanding the whole of the text from understanding the individual parts, and understanding the parts of the text in reference to the whole text: It is a recursive back-and-forth between the parts and the whole of text (Moules, 2002).

Once inside a hermeneutic relationship, the circle is a process of reciprocation. Being in the circle involves reading, writing, discussing, and reflecting on an understanding so that the understanding can be arrived at through language or text (Moules, 2002).

The notion of understanding from parts and wholes existed prior to the metaphor of the hermeneutic circle. Schleiermacher noted the circular pattern of understanding from parts and wholes, but intended it originally as a schema describing the process of
understanding versus a fundamental principle (Gadamer, 1960/1989). Gadamer insisted that understanding is always occurring in a circular motion, which is why the repeated return from the whole to the details, and vice-versa, is essential. Since the whole of understanding is relative, the hermeneutic circle is always expanding given it is continually being integrated with larger contexts. “The circular movement is necessary because nothing that needs interpretation can be understood at once” (Gadamer, 1960/1989, pp. 191-192).

When applied to textual interpretation, Gadamer (1960/1989) described the role of the interpreter being to “transpose ourselves into the perspective within which he [the author] has formed his views” (p. 292). It is the job of the interpreter to understand what might be true about the author’s view, how what the author has said could be right. Gadamer described that the task of hermeneutics is to establish agreement. This movement in and out of the data allows for consideration of that which might not have been initially visible, and enhances the understanding of the topic. Grondin (1999/2003) summarized “(t)he circle comes to describe the constant process of revision in the anticipations of understanding, in the light of a greater knowledge of the parts and in the name of a greater coherence of interpretation” (p. 81). Kvale (1996) offered that the end of this spiraling through a hermeneutic circle occurs when one has reached a place of meaning, free of inner contradictions, for the moment.

While most nurses do not work with texts, per se, I propose that the same concept of the hermeneutic circle exists in the practice of nursing. In order to gain an understanding, to formulate an interpretation, nurses must continuously move between “parts and wholes.” They must be contextualizing small bits of information within the
context of the bigger picture. For example, if a patient’s blood pressure is low, the nurse must determine if it is due to a drug that is known to temporarily decrease blood pressure, or if it is because the patient has a 40-degree fever and is now septic. Similarly, a child who complains of itchiness, could be due to an allergic reaction to the blood transfusion he is receiving, or simply due to dry skin. Regardless of the setting, nurses are constantly working with parts and wholes of information to formulate context and develop interpretations concerning their patients and the care they are providing.

*The fusion of horizons.* Gadamer (1960/1989) defined horizon as “(t)he range of vision that includes everything that can be seen from a particular vantage point” (p. 302). When applied to thought, the word horizon has been used to illustrate how thought is linked to “its finite determinancy” (Gadamer, 1960/1989, p. 302).

The concept of “horizon” suggests itself because it expresses the superior breadth of vision that the person who is trying to understand must have. To acquire a horizon means that one learns to look beyond what is close at hand – not in order to look away from it but to see it better, within a larger whole and in truer proportion. (Gadamer, 1960/1989, p. 305)

When we speak of “narrow horizons,” or “broadening one’s horizons,” we are referring to the relative range of openness of thought. Gadamer (1960/1989) offered that people with limited horizons overvalue what is closest to them, as they are unable to see past that which is in their immediate range of vision. People with broader horizons, however, can appreciate all that is within their range of vision, near or far, and realizes the significance of each. Our horizons are what we understand, based on our history, experiences, and prejudices.
When horizons fuse or when one’s horizon comes together with the horizon of another person or text, an evolution or change takes place and new understanding is created from this process. It is not that one understanding is better than another but together, through a fusion of horizons, a different, and perhaps better understanding, and then practice can take place (Koch, 1996). Gadamer (1960/1989) claimed that understanding occurs when horizons come together to form a new horizon. This fusion of horizons happens in conversation with another, with text, art, and others.

Reaching a fusion of horizons requires the interpreter to engage with the text in a productive way (Malpas, 2009). It is said to be something that is achieved tacitly, learning from others, versus following a prescribed method or theory. When hermeneutic interpreters approach text, they come with their own “horizons” – their prejudices that relate to their history and experience. Their horizons then fuse with the horizon of the text as interpretation occurs. The fusion of the two horizons allows the text to take on new meaning. Hermeneutic inquiry should aim for a fusion of the horizons of the interpreter and the text.

When approaching text for interpretation, hermeneutics asks that historical understanding (historical consciousness) be incorporated into one’s horizon. As much as possible, it asks that we place ourselves in the others’ situation in order to understand the significance of what is being communicated and to avoid misunderstanding (Gadamer, 1960/1989). The fusion of horizons occurs when the tension of the horizon of the text, and the horizon of the reader, is resolved (Gadamer, 1981). Our horizons are constantly changing as we learn, grow, achieve, think, and remember. They incorporate the present as well as the past.
Interpretation and Understanding: In Language, Dialogue and Text

“Language is the universal medium in which understanding occurs. Understanding occurs in interpreting” (Gadamer, 1960/1989, p. 389). At the heart of philosophical hermeneutics is the question, “How is understanding possible?” (p. xxx). Hermeneutics is synonymous with understanding. In this next section, I focus on Gadamer’s ideas of how interpretation and understanding occur in language, dialogue, and text, as these are inherently human modes of understanding (Binding & Tapp, 2008).

**In language.** Gadamer (1960/1989) explained that understanding is only possible because of our common bond of language. “Language is the medium in which substantive understanding and agreement take place between two people” (Gadamer, 1960/1989, p. 384). Our capacity to understand is intimately linked to language, and that mastery of language is a requirement of understanding (Gadamer, 1960/1989). Language contributes to the horizon through which the experiences of the life-world are understood. Gadamer encouraged careful examination of words, their history, context, and how we take them for granted.

Every word causes the whole of the language to which it belongs to resonate and the whole world-view that underlies it to appear. Thus every word, as the event of a moment, carries with it the unsaid, to which it is related by responding and summoning. (Gadamer, 1960/1989, p. 458)

According to Gadamer (1960/1989), we exist in language, and it is through language and dialogue that we gain understanding. It is through language that the world presents itself to us, however language is limited in its ability to express what Gadamer called the “*verbum interius,*” the inner word (cited in Grondin, 1994, p. xiv). Grondin (1994)
further explained, “the spoken discourse always lags behind what one wants or has to say, the inner word, and that one can understand what is said only when one derives it from the inner speech lurking behind it” (p. xiv). While language is limited and words are sometimes said to “fail us,” this speaks to the nature of hermeneutics as being limitless in its potential to create different understandings.

**In dialogue.** Gadamer (1960/1989) stated that conversation is the process of coming to an understanding, and introduced the concept of the “hermeneutical conversation” (p. 389). A hermeneutical conversation finds a common language, and it is within the process of finding common language, that understanding and reaching agreement occurs (Gadamer, 1960/1989). Gadamer suggested, “it is generally more correct to say that we fall into conversation, or even that we become involved in it” (p. 383). If we are intent on “conducting” a conversation, it loses its genuineness, and therefore, hermeneutic structure.

The way one word follows another, with the conversation taking its own twists and reaching its own conclusion, may well be conducted in some way, but the partners conversing are far less the leaders of it than the led. No one knows in advance what will “come out” of a conversation. Understanding or its failure is like an event that happens to us. (Gadamer, 1960/1989, p. 383)

In conversations, Gadamer (1960/1989) stated that the goal is a fusion of horizons, indicating that common understanding has occurred. As conversation is a process of coming to an understanding, it follows that in a genuine or hermeneutic conversation each person is open to accepting the other’s point of view as valid, with the intention being not to understand the individual, but rather to understand what the
individual has said. “In a conversation, when we have discovered the other person’s standpoint and horizon, his ideas become intelligible without our necessarily having to agree with him” (Gadamer, 1960/1989, p. 303).

In text. In order for interpretation to occur, there must exist something, some “text” (Ricoeur, 1998). Research done in the tradition of philosophical hermeneutics involves understanding parts of the text in relation to the whole, and understanding the whole as represented and understood through the parts (Cohen, Khan, & Steeves, 2000). Gadamer (1960/1989) insisted that the interview text represents a fusion of horizons, and that what is understood from the text is neither the participant’s, nor the interpreter’s, but the common – the fusion of horizons. The interpretation of text involves the horizon of the interpreter, and the historical horizon into which one places oneself when trying to understand the text. Thus, these horizons fuse to allow understanding to occur. The historical horizon of the text is not fixed; it cannot take on a meaning that is unchanged for all contexts.

Hence the horizon of the present cannot be formed without the past. There is no more an isolated horizon of the present in itself than there are historical horizons which have to be acquired. Rather, understanding is always the fusion of these horizons supposedly existing by themselves…Every encounter with tradition that takes place within historical consciousness involves the experience of the tension between the text and the present. (Gadamer, 1960/1989, p. 306)

Gadamer (1960/1989) also rejected the idea that understanding calls for eliminating one’s prejudices. The tradition of hermeneutics prior to Gadamer held that the meaning of a text is identical with the intention of its author. Therefore, the purpose
of interpretation was to reconstruct the author's intention, or original meaning. Gadamer claimed that understanding a text involves understanding the tradition to which it, and the interpreter, belong. As described earlier, he stressed the importance of being aware of one’s prejudices, not to hold them in abeyance, but so the text can assert “its own truth against one’s fore-meanings” (Gadamer, 1960/1989, p. 269).

Gadamer (1960/1989) also rejected the view that the author's intent in writing a text is of primary importance. “Not just occasionally but always, the meaning of a text goes beyond its author” (Gadamer, 1960/1989, p. 296). Once a text is created by its author, it becomes separated from the author and begins to take on new meaning based on its historical horizon and the changing circumstances of the present and future. When we try to understand a text we do not attempt to uncover what the author really meant, rather “we try to transpose ourselves into the perspective within which he has formed his views” (Gadamer, 1960/1989, p. 292). If our intent is to understand the text, we will, in fact, try to make the author’s arguments even stronger. Our understanding of the text changes as our historical horizon changes. Indeed, hermeneutics involves the reading of a text as the answer to a question that could have been answered differently (Gadamer, 1960/1989).

**Truth and Method in Hermeneutics**

The title of Gadamer’s (1960/1989) magnum opus, *Truth and Method*, hints of the centrality that these two constructs occupy in his philosophical hermeneutics. As Grondin (1999/2003) stated,

What Gadamer takes issue with is not the link between truth and method. The dependence of truth on method is so obvious that it would be useless to try to repeat it once more. What he criticizes is the method’s attempt to exercise a
monopoly on the notion of truth. (p. 3)

Gadamer challenged the notion of method as the only source of truth, and argued that historicity and tradition are essential to the hermeneutical task – the process by which we reach understanding. Truth, he claimed, cannot be adequately explained by method. Gadamer argued that hermeneutics is an activity that aims to understand the conditions that make truth possible, and within the human sciences its role is not the same as within the natural sciences. Hermeneutics is an investigation into the nature of understanding, and truth is not something that may be obtained by a particular method of inquiry. Truth, he argued, transcends method.

Central to the concept of truth in philosophical hermeneutics is aletheia, meaning “the event of concealment and unconcealment” (Caputo, 1987, p. 115). Aletheia, a Greek word, has an interesting etymological tracing and several meanings. The root of aletheia is lethe, from the river Lethe in Hades, a body of water the soul was transported over that was said to wash away memory as one transitioned to the underworld. Aletheia, then, is about remembering what was forgotten. Another meaning of aletheia is an opening of something once closed, revealing something once concealed, or an uncovering of something that was once covered. Moules (2002) offered the metaphor of opening the lid of a well, “flipping the lid open and letting it rest, allowing one to look into what lies beneath it” (p. 6). Necessarily, however, when one side opens, another closes, “for with every opening there is closure and some things are necessarily left behind” (Moules, 2002, p. 6). Finally, etymologically, aletheia is related to the word lethal, meaning “deadly, fatal” (Online Etymology Dictionary, 2012). A-lethal (aletheia) enlivens something that was dead. In philosophical hermeneutics, “truth” is not about discovering
how things “really” are; rather, truth is \textit{aletheia} \cite{Jardine,2006}. “Truth, in this hermeneutic sense, is a dance between revealing and concealing, between opening and closing off” \cite[p. 15]{Jardine,2006}. Gadamer \cite{1960/1989} claimed that hermeneutics is the practice of \textit{aletheia}.

In hermeneutics, objects are not fixed or given; they are interpreted, contingent things. Hermeneutics dispels the given-ness of things. It has a love affair with the ungiven-ness, always looking for the moment when something – when understanding – gets disrupted. It is always interested in events and how the event opens up what we took to be closed. It is aletheia. \cite[p. 14]{Moules,2002}.

Hermeneutics does not offer a method to obtain truth. It offers us a language to argue against the natural sciences’ claim on method being the only way to access truth. Hermeneutics reminds us that there is another way of knowing.

\textbf{Hermeneutics as Research}

Hermeneutics, as the art and practice of interpretation \cite{Gadamer,1960/1989}, aims to respond to the question: How is understanding possible? Interestingly, Gadamer did not provide a method for conducting a hermeneutic study. More specifically, he offered no “recipe” to follow, in exact order, with precision and clarity, to obtain results. Instead, hermeneutics offers a way to know and understand the world and thus, the topic \cite{Gadamer,1960/1989}. It is an interpretive methodology, which expects knowledge to emerge from dialogue in the form of an unpredictable discovery rather than a controlled outcome \cite{Annells,1996}. It is a reflexive inquiry where researchers are not considered as separate entities, or non-influencing factors, from that which they are researching.

“Hermeneutics is not founded upon the separation of researchers from the earthly life
they live or the lives that are the topics of their research” (Jardine, 2000, p. 105). With this in mind, in the remainder of the chapter, I detail the research design I employed in my hermeneutic study.

**Research Question**

My research question was: How might we understand the meaning of children's cancer camps for children and their families? This question has been generated through the impact of cancer camps and its initial “call” to me, personal experience nursing in the pediatric oncology setting and watching the children and families’ excitement of, and effect from, cancer camps, and the lack of research – particularly qualitative research – around children’s cancer camps.

**Recruitment of Participants**

The best individuals to include in a hermeneutic inquiry are ones that can best inform understanding of the topic (Moules, 2002; Smith, 1991). The number of participants needed in an interpretive inquiry is difficult to predict in advance (Smith, 1991) as it is rich descriptions of experience that extend understanding of the phenomenon of interest that is sought, versus a predetermined number. Measures of “power” and random sampling requirements used in quantitative studies to validate the number of participants are not used in a hermeneutic study (Koch, 1996; Morse & Field, 1995; Moules, 2002). In a hermeneutic study, it is the researcher’s aim to elicit a richness of data through the experiences of the participants – a process known as purposive sampling.

**Introducing the participants.** With the assistance of the Kids Cancer Care Foundation, six families, and five counselors were recruited and interviewed for this
The families were interviewed as a family unit, usually in their homes, and the counselors were interviewed in a focus-group setting at Camp Kindle, located in the Water Valley area of Alberta. All families had at least one member attend the 2012 summer cancer camp at Camp Kindle. Of the six families interviewed, all reside in Alberta, and all met the eligibility criteria as outlined in Appendix A. Families were interviewed (after obtaining informed consent) from 1 to 3 weeks after attending camp, while the counselors were interviewed on a Saturday afternoon, after the children and families had left camp (and before the next group arrived).

The Brown Family: I met with the Brown family in their home. Their two young children were present, although did not participate much in the interview. Their youngest child has leukemia and is currently on active therapy.

The Jones Family: I met with the Jones family in their home. The Jones have two children, although one was not present for the interview. The child that was at home did not participate in the interview, but was present nearby playing with his toys. Their oldest child had recently finished treatment for a brain tumor.

The Williams Family: I met with the Williams family at a local coffee shop in Calgary. Present at the interview were the mother, and the three children. While all three children, ranging from 9 to 14 years, participated in the interview, the youngest two became quickly distracted and left to play in another area. The middle child has been off therapy from Wilms tumor for approximately 10 years.

The Davis Family: I met with the Davis family at a public library in Calgary. Just the mother, Mrs. Davis, was present at the interview. She and her family recently
immigrated to Canada. Of her three children, her middle child is undergoing active treatment for a brain tumor.

The McMahon Family\(^1\): I met with the McMahon family, consisting of the mother, father, and four children, in their home. All of the children, ranging in age from 9 to 16, actively participated in the interview. The McMahon’s youngest child, Tanner, had passed away from leukemia approximately 6 years ago.

The Taylor Family: I met with the Taylor family at a hockey arena and interviewed just the mother, Mrs. Taylor, in a quiet room off to the side. Mrs. Taylor and her husband have two children, both with brain tumors (one benign, one malignant). Both children are currently receiving treatment for their brain tumors.

The Counselors: In total, five counselors were interviewed in the focus group. They ranged in age from 18 to 22 years, and they also ranged in experience; for some, it was their first experience as a counselor, and for others, they had worked as a counselor for many years. One of the counselors was a survivor of childhood cancer.

**Data Generation**

In a hermeneutic study, data is generated via semi-structured interviews with participants (see Appendix E for sample questions I used). The interviews with each participant were an open process, not defined by directive questions. This lack of structure or “rules” one is required to follow when interviewing participants, positions the researcher as being open to the other’s understanding and meaning of the topic. While interviews are unstructured, they were purposefully conducted and thoughtfully directed.

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\(^1\) While all names of participants are pseudonyms, the McMahon family has requested to have their real names used.
with the understanding that a skillfully conducted interview will produce data rich in meaning and ready for interpretation (Moules, 2002).

Transcribed interviews are considered data, along with context, tone of voice, pauses, and cadence in speech and emotional affect, but the data is not restricted to the interviews alone. To enhance the understanding and interpretation from the transcribed interviews, hermeneutics asks for consideration of setting and other external factors to be considered as data, alongside the transcribed interview. For example, my field notes and observations from the times I attended camp have also been considered in the data generation.

**Analysis and Interpretation of Data**

It is through the transcription process, reading and re-reading of the transcripts, reviewing of field notes, reflection on the interviews, and the generation of interpretations, that data was interpreted (Gadamer, 1960/1989; Grondin, 1999/2003; Moules, 2002). The process of how one goes from a transcribed interview to an interpretation that brings value, furthers understanding of the topic, and is *true of something* is challenging to explain in some respects, given that hermeneutics does not offer a defined method of conducting research or analyzing data. Jardine (2000) reminded us that some of what constitutes life is not measurable or analyzable by empirical means, and to make a topic conform to the likes of a technical method makes the topic technical in nature. In order to understand and bring forth meaningful interpretations from the data collected, the concepts of fusion of horizons and the hermeneutic circle were of assistance. The fusion of horizons, or the coming together of two or more understandings of the topic, coupled with the genuine curiosity of the
researcher and desire to understand the topic in a new way helped to further the understanding of the topic (Binding & Tapp, 2008; Koch, 1996). The hermeneutic circle – the metaphorical representation of looking at the whole and the parts, invited me to consider the particulars of the topic in the context of the familiar, and similarly, the familiar in the context of the particulars (Gadamer, 1960/1989; Grondin, 1999/2003; Moules, 2002). This movement in and out of the data allowed for consideration of that which might not have been initially visible, and enhanced the understanding of the topic.

It is also understood in hermeneutics that I, as researcher, came to this topic with experience and pre-understandings (or prejudices) about this topic. Jardine (2000) elaborated that the topic of research and the data from the research conversations cannot be separated from the current understanding or past experience (pre-understanding/prejudices) of the researcher. Our prejudices situate us within the topic such that we “see” and “hear” things we may have not have otherwise seen or heard (Moules, 2002).

**Ethical Considerations**

As per the requirements of the University of Calgary, before proceeding with this research, approval from the University of Calgary Conjoint Health Research Ethics Board was obtained. Approval from Kids Cancer Care was also obtained, specifically from Christine McIver (Chief Executive Officer), Mike MacKay (Director of Camp and Community), and Jordan Miller (Camp Program Manager). Camp staff (e.g., counselors, nurses) were made aware of my purpose for attending camp, and families at camp were also informed of the reason for my presence. In addition, field notes and observations were related to the general camp experience and were not about any of the individual participants.
**Consent and confidentiality.** Prior to the interviews, informed consent (or assent, if applicable) from participants was obtained (see Appendices B, C, and D). This included consent to be interviewed, to have the interview digitally recorded, and to have the findings published and presented. All names have been changed to pseudonyms, and transcripts will be kept confidential and stored in the secure office of the Principal Investigator for a period of 5 years. Data files were kept on a password-protected computer. Any direct quotes used in this thesis or other publications have been (and will be) screened to ensure that identification of the individual is minimized, however, participants were made aware that despite every effort, the possibility exists that they could be identified when data is made public through publication and presentation.

**Risks and benefits.** Prior to each interview, in addition to obtaining informed consent/assent, a brief overview of the study and explanation of the purpose of the research was offered. Participants were reminded that their participation was voluntary, and they had the right to withdraw from the study at any time. Should they have decided not to participate, they were assured that in no way would their care, or the care of their child, be jeopardized. Given the nature of this topic, it was not anticipated that participants would encounter undue stress while taking part in the interview, however had this happened, I would have referred the participant to Dr. Nancy Moules, an experienced counselor in the areas of pediatric oncology, families, and grief. In addition to this verbal explanation, a written copy of the above was provided, signed by both participant and researcher.

I also explained that results from this study may contribute to understanding how cancer camp provides benefit for children and their families, and serve toward improving
upon these camps and the programs they offer. Additionally, the results may assist in “legitimizing” the camp experience, and targeting camping programs as interventions used to improve psychosocial health and outcomes.

**Hermeneutic Research and Cancer Camps**

Moules, McCaffrey, Laing, Tapp, and Strother (2012) offered that there is a natural fit of hermeneutics with pediatric oncology as the experience of cancer is an interpreted experience, unique for each family. “Hermeneutics… allows us to make sense of the particulars of families’ experiences and arrive at deeper understandings of how families experience the angst, fortitude, and capacity to learn to live alongside life events that call forth the unimaginable” (Moules et al., 2012, p. 7). Children’s cancer camps, falling under the umbrella of pediatric oncology, are also experiences unique to each child and family, and this inherent complexity cannot be understood through traditional quantitative means alone. No two children will experience camp in the same way, approach it with the same outlook, and take from it the same experiences. The understanding gained from an interpretive inquiry is key to “becoming more effectively, skillfully, or humanely engaged in practice” (Benner, 1994, p. xv) and is a particularly useful approach when one seeks to understand meaning and practices that are often taken-for-granted and assumed (Moules et al., 2012).

**Concluding Thoughts: Reflections on Hermeneutics**

Hermeneutics has been defined and described in many ways: It is “an art and not a mechanical process” (Gadamer, 1960/1989, p. 191); the practice and theory of interpretation and understanding in human contexts (Chesla, 1995; Grondin, 1994; Moules, 2002); “(h)ermeneutic work is based on a polarity of familiarity and
strangeness” (Gadamer, 1960/1989, p. 295); (h)ermeneutic understanding is characterized by engagement in reflective activity and asking questions (Chesla, 1995); “(t)he true locus of hermeneutics” (Gadamer, 1960/1989, p. 295) is found in the space between what is said and what is left unsaid. It is a tradition with a long history and numerous influencers, many of whom have not been named in this chapter. At some point, however, one who chooses to undertake research in the tradition of philosophical hermeneutics must understand what hermeneutics is for him or her. Aristotle (1459) said, “To make a good metaphor means to recognize similarity” (cited in Gadamer, 1960/1989, p. 431), and it is with this in mind that I offer some thoughts on how I have come to see hermeneutics.

Hermeneutics is the green spaces within a city. It is the place to go and reflect, watch, absorb, understand, and breathe. It is where the oxygen is the most abundant and the clarity resides. I have come to see the concrete-ness of a city’s structure (i.e., its buildings) akin to the natural sciences and quantitative research, but that alone does not draw the appeal of a city. You need the green spaces too, even more perhaps, in order to live in a concrete jungle. Hermeneutics connects us to what was, what is, and what will be. It calls on us to remember what was forgotten, to enliven or bring back to life that what was once “lethe,” and reminds us that things have “always, already” existed.

I have also come to think of hermeneutics like the corpus callosum of the brain. The corpus callosum connects the hemispheres of our brain – our right brain to our left. It is a thick band of nerves deep within the brain that allows the two hemispheres to communicate and coordinate their activities (National Organization for Disorders of the Corpus Callosum, 2009). Most, if not all, of the communicating of motor, sensory, and
cognitive information between the two hemispheres happens through the corpus callosum. This “connecting” activity, the “bringing together” of diverse information and producing something meaningful, is what hermeneutics does best. It makes sense of chaos, finds truths in narratives, and links together ideas in such a way as to make them intelligible and understood.

“Reason is why we survive, but without emotion there is very little quality to our existence” (Courtenay, 2008, p. 374). “Reason” has always been given preferential treatment. Indeed, there exist truths in this world that are best obtained by scientific means – by reason – than by any other method. Gadamer (1960/1989) sought to justify the relevance of the humanities and show the possibility and importance of non-scientific truth. He did not dispute the merits of the natural sciences – he disputed their monopoly on truth. The ways of finding truth in the natural sciences are not always adequate for human life, and Gadamer attempted to recover the memory of what was occluded by the natural sciences. While modern science casts a shadow on what it means to “know something,” hermeneutics points to the fact that much of what happens to us – though anecdotal – contains truth. What the human sciences want to talk about cannot be achieved procedurally. Life itself has a hermeneutical structure; the world is gendered and not neutral, as the natural sciences claim. The natural sciences ask you to erase yourself with respect to the phenomenon. Hermeneutics starts when we realize something is going on, something is happening. It is interested in things that happen to us – not only in what they might mean, but of what they might be true.
Switching Gears

The remainder of this thesis is related directly to my research around children’s cancer camps. It requires a mental “switching of gears,” of sorts, as the reader will notice a change in the style, tone, and cadence of the writing, as well as the type of language used. In these next chapters, I offer an engagement in the world of children’s cancer camps and the lives of these families who live with the diagnosis of childhood cancer. It is appropriate that at this point hermeneutics, as a topic, needs to disappear into the background while the topic takes center stage.
Chapter Four: In Play, At Play

Situated in the middle of a beautiful nowhere lies 160 acres of land best described as God’s country. Dense forest and rolling hills against the backdrop of a never-ending blue sky, Camp Kindle is not just beautiful, it is excessively, indulgently, indefensibly beautiful. Its newly renovated buildings and wide-open spaces invite possibilities and whisper of opportunities to those who stay within its boundaries. As I made my way across a newly sodded part of a field, a little girl of about eight ran to catch up with me. “Didn’t you know you’re not supposed to be walking here? It’s new grass, you know – it needs time to grow. What’s your name? Are you a counselor? Are you someone’s mom?” she rapidly fired me with questions the way only a young child without the burden of ego can. Her approach made me giggle and we talked as we made our way towards the lodge, me grateful to have someone to show me where I was going on my first day at camp. I came to learn that Molly was in her third year of treatment for leukemia and was at camp with her older sister and parents. She had been to camp a lot she said, “too many times to count” in fact. She seemed curious about my purpose for being there and did not seem to accept my answer of “research.” I decided to try a little harder: “I’m going to be talking to kids and families, and even the counselors, to see if I can understand what it is about camp that’s so great.” She contorted her face as if that was the stupidest thing she had ever heard, and blurted out, “THAT’S EASY! IT’S SO MUCH FUN!” I laughed at her distaste for my research topic, realizing this girl was not letting me off the hook, and debated with myself how much further I would persist. Molly quickly grew bored however, and instead launched into a new conversation with me about how lots of the

\[^2\] Portions of this chapter have been published in the Journal of Applied Hermeneutics as “In Play, At Play.”
kids at camp are bald you know, and she used to be bald but isn’t anymore, and some kids are missing a leg or an arm, and some have scars, and her only scar is from where her port is, and do I have any scars, and oh! have I been on the giant swing because she’s been on the giant swing and she used to be afraid of it but now she loves it…and I kept my mouth closed and smiled and just listened to the flood of enthusiasm she washed over me.

I was expecting camp to be fun. My preconceived ideas and understanding were that lots of play and lots of fun happened at camp. I arrived at camp looking for evidence of this and I found it easily. From the counselors’ “camp names” (e.g., Fish, Orca, Lupin, Starry) to songs at mealtime (e.g., the elbow song) to the high ropes course, giant swing, initiatives course, and arts and crafts (to name only a fraction of what could be named), there is no doubt that camp is structured in such a way as to maximize the fun. What I did not expect, however, was to discover through my observations and research interviews all that was at play, at camp. So much is at play, in fact, that I would suggest this to be the fundamental phenomenon from which all further interpretations arise. For example, in subsequent chapters, I will present interpretations centered around fit and acceptance, grief, community, and stories, however these interpretations all stem from what is at play, in children with cancer and their families, at cancer camp. This will be explained further as each interpretation is presented.

Perhaps synonymous with camp is the thought of fun and play. Most of the children in my research wanted to talk only about the fun things they did at camp, the playfulness of their time there. In this chapter, I will offer only a few quotes from the children related to play because they are mostly homogenous in nature. My experience
interviewing the children was that, for the most part, they only wanted to talk about what they did at camp – the games, the activities, the fun. When asked questions related to what they enjoyed most about camp, answers like “giant swing,” “dumping water on counselors,” “high ropes,” “out trips,” “zip-lining,” “the dances,” and “campfires” were all common responses. In other words, a list of what they did was what they offered in response to most questions directed around camp. For them, camp is about what they do, not how or why they do it, and any effect camp may or may not have had on them was, with only a few exceptions, generally unnoticed by them. Indeed, this may be thought of as a limitation to this research (and will be discussed in Chapter 7 of this dissertation), however as stated earlier, I have come to see that it is not so much what they play, rather what is at play.

The word “play” is deceptively ordinary. It likely conjures images of children, games, or a dramatic performance, however almost 100 definitions and idioms exist in reference to this word. We can play and be played, something can be at play or come into play, we can watch a play, play with words, play around, make a play for, or play along. Play is “complex and slippery” (Brown, 1998, p. 243) because the more one looks into, under, and behind the word, the more one discovers its history, roots, uses, and meanings. As a noun, play is defined as the conduct, course, or action of a game, or a recreational activity (Merriam-Webster, 2012). As a verb, it means to engage in sport or recreation; to move aimlessly about; or, to perform music or to act in a dramatic production (Merriam-Webster, 2012). Etymologically, the origins of play are unknown but thought to come from old English plegian (verb), to exercise, frolic, perform music, and plæga (noun), recreation, exercise, any brisk activity (Online Etymology Dictionary,
Throughout its etymological history, “play” has been closely connected to the world of children and make believe, and has generally stayed true to its primary meaning (Online Etymology Dictionary, 2012).

Much has been written about play both philosophically (e.g., Gadamer, 1960/1989) and scientifically (e.g., Bjorkland & Pellegrini, 2000; Brown, 1998, 2009) to the extent that there now exists institutes and university programs devoted to the study of play. In this chapter, I do not intend to comprehensively cover the vast literature on play; rather my intent is to interpretively examine the phenomenon of play in relation to children’s cancer camps. While there is an obvious association between play and camp, I would suggest that, like the word itself, there is more complexity in this relationship than what first appears obvious. Children play at camp, of course, but there is much “at play” in them when they attend camp. As Gadamer (1960/1989) would say, “something is going on…something is happening” (p. 104).

It is important to note, before further discussion, what Gadamer meant by play. Gadamer’s work was written in German and later translated to English, and while play (the verb) and game (the noun), are different words in English, in German it is the same word (e.g., play a game, ein Spiel spielen). Play, from a Gadamerian perspective, is not about games per se, but rather more about what Miller (1996) described as “leeway.” Miller recounted a story of himself as a young academic under the mentorship of Gadamer. He recalled asking the philosopher, “What is the point of play?”

Gadamer asked me if I rode a bicycle. I said that I did. Then he asked me about the front wheel, the axle, and the nuts. He remarked that I probably knew that it was important not to tighten the nuts too tightly, else the wheel could not turn. “It
has to have some play!” he announced pedagogically and a little exultantly, I thought. And then he added, “... and not too much play, or the wheel will fall off.” (Conclusion section, para. 4)

A leeway is an allowable margin of freedom or variation, the amount of freedom to move or act that is available (Merriam-Webster, 2012). Perhaps it could be said that the intent of this interpretation then, is to explore the margins of freedom and variation to move and act – to play – that children have at cancer camp; the intent is to examine the space between where their restrictive lives at the hospital and home end, and where their lives at camp begin.

**Playing at Camp from a Philosophical Perspective**

I spent many days at cancer camp throughout the course of my research. I had the opportunity to immerse myself in daily life with these kids and families, and while I had numerous moments participating, I had just as many moments watching. Watching these kids I knew so well outside of the hospital environment, some of who were at one point sicker than I care to remember in great detail, some whose number of days in hospital neared the number of days out of hospital and some, it was clear, whose time at camp this year would be their last. These experiences (in italics) are used to illustrate the phenomenon of play.

1. You could hear them coming before you could see them. The thundering clamor of the buses rolling along the bumpy dirt road leading to camp, and the voices, the cheering, the songs (a warbling hybrid of several, it seemed), the exuberation – all as if to say “we’re finally here!” As the buses turned the corner and the camp came into view, the promise of the week ahead took over any remaining restraint and the sound
became deafening. One by one they exited the bus until a sea of bald heads, broviacs, and feeding tubes filled the empty, waiting space of camp. There was no mistaking – these kids were here to play.

Play, according to Gadamer (1960/1989), is not to be understood as something someone does, rather the structure of play absorbs the player into itself, freeing them from the burden of initiating play. It is movement without purpose or goal, renewing itself through repetition and absorbing the player into its movement. Gadamer offered that it is only when a player loses him/herself in play that the purpose of play is fulfilled.

Play is not a disengaged exercise of subjectivity, rather it is something that has its own order and structure to which one is given over. It is not to be thought of as an object upon which a player (or spectator) acts, nor can it be understood as a subjectively determined activity. Gadamer (1960/1989) maintained that “play is really limited to presenting itself. Thus its mode of being is self-presentation” (p. 108).

It was interesting to watch the children exit the bus, some knowing what they were in for, others riding the wave of their peers’ excitement. There was an element of them “being taken over,” entering into a moment beyond their control – one in which they did not initiate or intend to enter – rather, it just happened to them. It was the beginning of something happening, something was at play here and looking back upon it, through this particular lens of philosophical hermeneutics, I can now see this moment differently. I can see the to and fro-ness of this moment, not from a game perspective, but from a losing of oneself to a moment, over and over, perspective. The children did not arrive at camp intending to absorb themselves, and fulfill the purpose of play by “losing themselves” (Gadamer, 1960/1989). Rather, “over and above their wanting and
doing” (Gadamer, 1960/1989, p. xxviii) they entered into the margins of freedom and variation to move and act that they did not experience in their day to day life – the leeway, the play of things. Something was clearly at play.

II. I watched her make her way up to the giant swing and giggled nervously. She was scared, you could tell. Well, I could tell, because it was the same look she would get when I had to inject L’asparaginase into her thigh. I had seen that look 24 times, we counted one day. She was strapped into a climbing harness so I knew there was no way she could get hurt, but I’m not sure she knew that. The other kids, sensing her trepidation, buoyed her on with cheers of “you can do it!” and, “you’re almost there!” Finally, the countdown, “3...2...1...go!” and the swing was released, sending her on a giant arc back and forth through space and time, her face awash with exuberant bliss.

Central to Gadamer’s (1960/1989) notion of play is the back and forth-ness, the “to and fro motion” (p. 104), where “what characterizes this movement back and forth is that neither pole of the movement represents the goal in which it would come to rest” (Gadamer, 1986, p. 22). Play appears as movement without purpose or end point, renewing itself through repetition. It takes on the burden of initiative, absorbing the player into its movement. Play exists “to play.”

The giant swing, going back and forth with a momentum of its own, requiring no initiation or continuation to keep going on the part of the swinger, brings to mind Gadamer’s (1960/1989) notion of the to and fro of play. “The structure of play absorbs the player into itself” (Gadamer, 1960/1989, p. 105), however as McCaffrey, Raffin Bouchal, and Moules (2012) noted, “there has to be more than one player, and there is a to-and-fro movement between players with a spontaneity and creativity in the motion of
the play” (p. 223). This additional player can be metaphorical. What Gadamer is referring to is that in order for play to occur, something needs to respond to the person playing. It can be a person catching a ball that has been thrown by another, or it can be the giant swing responding to the girl’s desire to swing.

In some cases, as in Rilke’s poem that is the epitaph in Gadamer’s (1960/1989) *Truth and Method*, a person is drawn into a game, into play, without initiative or intention.

Catch only what you’ve thrown yourself, all is mere skill and little gain;
but when you’re suddenly the catcher of a ball thrown by an eternal partner with accurate and measured swing towards you, to your center, in an arch from the great bridgebuilding of God:
why catching then becomes a power – not yours, a world’s.
(cited in Gadamer, 1960/1989, p. v)

Being “the catcher of a ball thrown by an eternal partner” illustrates the nature of being drawn into play without initiation. When we are engaged, we lose our subjectivity and become “played” by the game, subject, or conversation within which we are engaged. We do not consciously think, “here I am AND I am caught up in this game” – that awareness is lost. We have let go of ourselves being the ones responsible for conducting the way it goes. It is a curious thing, to consider what it is that gets lost when you lose
yourself in something. When children are at cancer camp, I wonder if, when they lose
themselves in play, they paradoxically find something else. Perhaps with this losing of
themselves, they are finding acceptance, joy, and confidence.

III. “1, 2, 3, a-Larry”...I hadn’t heard that rhyme since elementary school. No,
before that. I thought it was “one of those songs” my mother had taught me, dating back
(as far as I was concerned) to the olden days. “4, 5, 6, a-Larry”...while I knew the song,
the game had changed – I was trying hard to figure out these new rules. Four kids were
passing three balls among each other at increasing rates of speed – seemingly trying to
get each other to drop the ball. Who knows the point, really, that’s irrelevant. I became
comfortable with the mystery of it. “7, 8, 9, a-Larry”...they seemed so engrossed in what
they were doing, so serious. They didn’t hear the dinner bell ringing or the cacophony of
general camp noise. They were taken over by the game. “10, a-Larry CATCH ME!”

“Play fulfills its purpose only if the player loses himself in play” (Gadamer,
1960/1989, p. 102). Gadamer (1960/1989) noted that there is a seriousness to play that is
required to make the play “wholly play” (p.102). This seriousness, however, belongs to
the play itself versus to the player. Gadamer reminded us many times that the players are
not the subject of play; “instead play merely reaches presentation through the players”
(p.103). “Movement as such” is the essence of play, which has no goal but constantly
renews and repeats itself. There is a primacy of the game over the players and of the play
over the consciousness of the player (Gallagher, 1992). As such, it is not the player who
plays the game, rather the game plays the player: “(A)ll playing is being played. The
attraction of a game, the fascination it exerts, consists precisely in the fact that the game
masters the players” (Gadamer, 1960/1989, p. 106).
This dominance of play over the consciousness of the player is easy to see when you look for it. I see it in my 3-year old when she plays “pretend;” I notice it in myself after the fact of being engrossed in a game, and I realize now that was what I was witnessing when I watched the game the children were playing at cancer camp. They were playing, but there was also something at play in them. I feel the need to name this – to figure out what it is that is at play during these moments in these children. Surrender, transcendence, giving-over, and vulnerability are all words that come to mind, however, these words do not entirely capture what I think is happening, what is at play. Perhaps Gadamer would have said that the point is to realize that there is something at play here, and correctly naming it is not the spirit of hermeneutics. It is not about being right, rather hermeneutics is about finding an interpretation that is true of something. Like art, play, and games share a to and fro movement not bound to a specific goal other than fulfilling themselves (Gadamer, 1960/1989). It is what occurs when the game is in play that matters. Over and above their wanting and doing, the player is taken over by the play which has no purpose other than to bring something forth (Gadamer, 1960/1989).

IV. They were deep in conversation, it seemed. I don’t know what they were talking about but it was fun to watch them as they sat on the picnic table in their own world, despite being amidst the chaos of camp. In my mind, I imagined they were discussing their diseases, how they were managing chemo, what it was like to be teenage girls without hair. In reality it was probably something much more “normal” than that – boys or clothes, maybe. Their expressions changed as they took turns being the speaker and the listener, and each seemed to take the role of listener very seriously. More serious
than most teenage girls do, I think. I couldn’t help wondering, for the rest of that day, what were they talking about?

Gadamer (1960/1989) used the concept of conversation and the phenomenon of play to describe the dialogical nature of understanding. In comparing understanding with acts of dialogue and play, Gadamer suggested that the process of question and answer, listening and speaking, and seeing others’ points of view, enable us to reach new understandings (Spence, 2005). When in a genuine dialogue with another, we try to understand how what the other person is saying could be right (Gadamer, 1996). In a genuine conversation, the concern is with the subject matter and with its possible truth (Warnke, 1987). Neither participant claims to know the truth; rather, each is open to the other’s views. “Thus, being in the play of different understanding makes possible a movement, on the part of the players, towards ways of knowing that extend beyond their current understandings” (Spence, 2001, p. 627).

Watching the girls in conversation, the cadence of their dialogue having a visible, almost predictable “back and forth-ness” to it, draws attention to Gadamer’s analogy of play having a dynamic and influx nature (Spence, 2001). “The naturalness of the movement, the immanently dialectical relationships and the process of playing out possibilities” (Spence, 2001, p. 627) has me play with the possibility that that is exactly what was really happening with these girls. Perhaps they were playing with possibilities, trying on each others views, listening to hear if what the other was saying was true of something for them, or coming to new understandings. Whether their conversation was “genuine” or “hermeneutic” in nature I cannot be sure. I can be sure, however, that in the back and forth, and to and fro-ness of their dialogue, something was at play.
Playing at Camp from a Scientific Perspective

V. CML (Interviewer): What is it you think, I mean if you were to try and describe this to your friends or to somebody that didn’t have the same experiences as you – if they said “why do they [the kids] like camp so much?” – how would you respond?

Father: I think for Abby it allows her just to be a kid, you know, not have to worry about cancer. Not have to worry about – I mean there’s people there that understand her medicines and I mean, we don’t have to worry about it either – that she’s not getting her medicines or that she’s, you know, taking chemo and then eating right away or whatever.

CML: Because you know that’s taken care of?

Father: Yes. Cause they – I mean, I have no idea how they do it, they just magically make everything happen when it’s supposed to!

It is surprising for many people to learn how restricted children with cancer are, both in their daily activities as well as in the bigger, more significant events in their lives. The treatment for cancer often leaves children with significant immune suppression, meaning exposure to any kind of virus or infection could lead to a life threatening event. Pediatric cancer programs teach parents how, and when, to limit their child’s activities and exposure to others, and many families find their times of restriction far outweigh their times of freedom. School, social events, and birthdays are only some of the activities often missed because of their disease. Summer camp (for healthy children) is another opportunity these children could never conceivably attend due to the risk of exposure to infection and also because of their associated medical complexities (e.g.,
central lines) that require care and attention. Summer camp – a “rite of passage” for many kids – would be a forgone experience were it not for these specialized cancer camps.

The importance of cancer camps can be further substantiated by what is known about play from the scientific community. “Play, more than any other activity, fuels healthy development of children – and, the continued healthy development of adults” (Perry, Hogan, & Marlin, 2000, para.5). Our bodies, minds, and words are all involved in play, and while the nature and complexity changes as a child grows, at the heart of play is pleasure and a powerful desire to repeat such activities (Perry et al., 2000). It is through this repetition that mastery occurs, leading to accomplishment and self-confidence.

From a neuro-developmental perspective, play is the building block to learning. We learn through repetition and, because of the desire to repeatedly engage in play, all learning – emotional, social, motor, and cognitive – is fueled by the pleasure of play (Perry et al., 2000). Piaget (1962) proposed that it is through cooperative, social play that moral reasoning develops. The concept of play has been the focus of many research studies examining its effects on memory (Greenough & Black, 1992), growth of brain cells (Gordon, Burke, Akil, Watson, & Panskepp, 2003; Huber, Tonini, & Cirelli, 2007), intelligence (Bjorkland & Pellegrini, 2000; Pellegrini & Holmes, 2006; Stevenson & Lee, 1990), language (Fisher, 1992; Lewis, Boucher, Lupton, & Watson, 2000), problem-solving (Pepler & Ross 1981; Wyver & Spence 1999), and mathematic abilities (Wolfgang, Stannard, & Jones, 2001).

Children and adolescents lack the ability to communicate complex feelings through language. Emotions such as frustration, sympathy, and ambivalence are difficult
for them to express because of their concrete view of the world (Landreth, 2001). Playing allows for the expression of these emotions. Play has biological, cultural, social, and psychological functions (Landreth, 2001), and is considered of such importance that it is used as a therapeutic modality (called play therapy) in pediatric hospitals around the world.

McMahon (2003) wrote:

We need to play…play is not a mindless filling of time or a rest from work. It is a spontaneous and active process in which thinking, feeling and doing can flourish since they are separated from the fear of failure or disastrous consequences. (p. 197)

Failing and disastrous consequences are what children with cancer live with every day. Play provides not only an escape from their disease but a way in which they can continue along the journey of being a child, learning what is required of them, mastering what they need to, and finding enjoyment along the way.

Gadamer (1996) stated that it is only through experiencing illness that we understand health. I would further this idea to mean that sometimes we can arrive at understandings though the negative – understanding what is because of what is not.

Perhaps examining the absence of play – playlessness – could help to further the understanding of what is at play in children who attend cancer camp. Brown (2009) offered a metaphor comparing play to oxygen – “it’s all around us, yet goes mostly unnoticed or unappreciated until it is missing” (p. 6). His team’s research into violent criminals (most notably Charles Whitman, the Texas tower mass murderer) found that “normal play behavior was virtually absent throughout the lives of highly violent, anti-
social men, regardless of demographic” (Brown, 2009, p. 249). Similarly, Goodall (1986) wrote of the murder – cannibalism by Gombe female chimpanzees, noting that chimps displaying this rare behavior were ineffectively mothered, with early play and later socialization patterns constricted.

It would indeed be a stretch to say that children with cancer, deprived of play, will become adults with violent tendencies, but as Brown (2009) noted:

I now perceive healthy varied play in childhood as necessary for the development of empathy, social altruism and the possession of a repertoire of social behaviors enabling the player to handle stress, particularly humiliation and powerlessness. I also have found that general well-being and play are partners, and that it accompanies the most gifted in their adult achievements: Perhaps it allows access to the giftedness we all possess. (p. 250)

Perhaps it is more responsible to say that children with cancer who are deprived of play because of the limitations of their disease may not be getting the same chances as their peers. The same chance to learn the skills they will need in adulthood, to learn about themselves and others, and to reach their full potential. Some may defy the odds and do it anyway – but I wonder, why would we take that chance?

**Concluding Thoughts**

Benner (1994) suggested that the understanding gained in interpretive inquiry is key to “becoming more effectively, skillfully, or humanely engaged in practice” (p. xv) and is a particularly useful approach when seeking to understand things that are taken for granted or assumed. Play, I believe, is one of those taken for granted things. It is all around us, until it is not. Like oxygen, its absence is noticed, not its presence. My
experiences at camp and interviews with the families, combined with the lens of philosophical hermeneutics and other play research, illuminate the concept of play in such a way as to further the understanding of this phenomenon (play) in this setting (cancer camp). I have not yet answered the question of exactly what is at play in these children when they attend camp, but in the subsequent chapters, I bring forth my interpretations and understandings I have gained by interviewing these families, in hopes of illuminating what is at play, at camp.
Chapter Five: The Island of Misfit Toys

Um, I know this sounds really weird but sometimes I think of camp as the Island of Misfit Toys cause there’s all something - we’re all damaged in some kind of way, and then it’s just amazing to see the kids - they’re so proud of who they are when they come to camp. The camper that comes to mind is Liam...he’s just, I mean ah, he has his leg amputated and he calls his little stump Tiny Tim (laughs). I mean, outtrip [an overnight camping experience], like he was just telling a story and showing off Tiny Tim to all the campers cause they’re all curious about it...he’s just so proud of himself and I think it’s just fantastic to see, and it really inspires the other kids in the group. I noticed since he told his story other kids have come out of their shells and they’re just, they’re like, you know what, it’s ok to be who I am – something might not look quite right, but it’s ok cause we’re all here together.

(Counselor)

The Island of Misfit Toys was an addition to the classic Christmas story of Rudolph the Red-Nosed Reindeer, originally airing in 1964. It is an island sanctuary where defective and unwanted toys are sent, including, among its inhabitants, a cowboy who rides an ostrich, a train with square wheels, a squirt gun that shoots grape jelly, and an airplane that cannot fly (Wikipedia, 2012). I remember watching this show as a child, and feeling badly for these forlorn toys, rejected from Santa’s sack because they were imperfect. It seemed unfair to me, even at a young age, that something could be rejected or excluded due to imperfections. The counselor’s comparison of camp to the Island of Misfit Toys struck me as a perfect metaphor for what I had noticed at camp, but up until the point of her saying it, was unable to articulate.
Before further discussion a closer examination of the word *misfit* is warranted. Merriam-Webster (2012) defines *misfit* as “something that fits badly,” or, “a person who is poorly adapted to a situation or environment.” It is an interesting word from an etymological perspective, with *mis* meaning “in a changed manner,” and with a root sense of “difference, change,” and *fit*, coming from the early 15th century, meaning “suitable” (Etymonline, 2012). It is not my intention to dissect this word into infinitesimally small pieces, however I wish to draw attention to something important as sometimes deconstructing words such as this offers a different lens from which to understand, or at least challenge, the traditional meaning. When you separate *mis* from *fit*, and examine them as two distinct words, the word *misfit* can be understood differently. *Misfit*, from an etymological standpoint, can be understood as something, or someone, that is “differently suited” versus the traditional definition offered earlier of “a person who is poorly adapted to a situation or environment.”

Cancer camp, like the Island of Misfit Toys, offers a “sanctuary” of sorts, a place of belonging, acceptance, and safety. There is no such thing as someone who does not fit in, in fact “*usually the quirky kids get pulled into the group the fastest*” (Counselor). Before examining this culture of acceptance and how these children are “differently suited,” it is important to first look at how it is children with cancer stand out and often feel unaccepted in the “real world.”

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3 The “real world” is the language most children and families used in my interviews when describing life outside of the camp environment. I have chosen to adopt this language when describing the same.
Understanding Fit: From Misfit to Fitting In

Mother (talking about the kids at camp): There’s a variety of different types of challenges and everybody just kind of accepts that that’s where they are, they’ve got theirs you’ve got yours and it moves on. Everybody’s got their issues, they’re all quirky, they’ve all got their challenges, so what?

Father: But outside the general, you know, the outlook, um, it’s a little different, it’s a little more harsh, a little less acceptance. (Parents of a child with a brain tumor)

Most of the families who spoke about camp being a place of acceptance had a child with a visible or behavioral difference that distinguished them from their peers. From loss of hair due to chemotherapy, to brain tumors, radiation therapy, or unrelated concurrent illnesses or syndromes (e.g., Asperger’s/Autism, ADHD, etc.) most children who have experienced cancer have also experienced looking, or being, different from their healthy peers at some point along the cancer trajectory. They have experienced a mis-fit in the real world, and all of the accompanying challenges. We know from the literature that “peer relationships are an important index of a child’s current social competence and psychosocial adjustment” (Vannattaa, Gartstein, Zellerc, & Noll, 2009, p. 303). Establishing relationships with peers is a major developmental task of preadolescence and adolescence (Sullivan, 1953) and provide an important context for learning social skills and mastering the complexities of cooperation and competition (Hartup, 1999; Rubin, Bukowski, & Parker, 2006). I offer that it is by being completely, unconditionally accepted at camp, that these children come to understand that they are differently suited to their environment.
Matthew got to be Matthew, he wasn't judged. I mean they all have quirks – I mean some of them can't see and stuff – that cancer affects, so he didn't feel like he was standing out and he tried things. I mean he did the flying squirrel! (Mother)

According to Chilean biologist Humberto Maturana, acceptance and love originate from the same source. He defined love as “the spontaneous dynamic condition of acceptance by a living system of its coexistence with another (or others) living system” (Maturana, 1986, p. 59). Love, he offered, involves “opening a space of existence for an other in coexistence with oneself on a particular domain of interactions” (p. 59). Norris (2009) further troubled this notion of love by noting that in Buddhist thought, the ability to open space is something that can be intentionally cultivated. From a biological perspective (Maturana) to Buddhism, there are parallels between love, acceptance, and space. I find this particularly fitting, given the landscape on which camp resides. It is open and spacious, as if to be the literal interpretation of Maturana’s notion of love. The open spaces of camp are defined by the structures around them – the trees, the pond, the lodges, and the other various structures that occupy this space. It is in the empty spaces though, the “between-ness” that brings to mind a poem in the Tao Te Ching entitled The Utility of Non-Existence:

Though thirty spokes may form the wheel,
it is the hole within the hub
which gives the wheel utility.
It is not the clay the potter throws
which gives the pot its usefulness,
but the space within the shape
from which the pot is made.

Without a door, the room cannot be entered,

and without windows it is dark.

Such is the utility of non-existence.

(Taoism Information Page, 2004)

Like the hole in the hub of the wheel, it is perhaps in the empty spaces of camp where the most value lies. The buildings, ropes course, and campfire pit provide the structure (spokes) around which the wheel turns. The essence of camp, however, lay in the spaces between, as it is here that acceptance and “fit” is found.

It is not just the children with cancer who find acceptance at camp. Siblings too, described a sense of relief being in the camp environment:

"I like how, well, in my dorm we were talking about sometimes at school and stuff people don’t really know. They say, “oh we know what you’re going through” but they don’t really, so when we come to camp everybody knows what you’re going through and you like, fit in. (Sibling)"

"Well, sometimes at school, when I was in grade one when it first happened [sibling diagnosed with cancer], people thought that um, like I had it, like it was contagious, like they could catch it from me, and everybody started avoiding me and stuff like that. But then it started to pass by, but I always remembered that. When I went to camp it just went away, like I forgot about that. (Sibling)"

I believe there is a profound change that happens to children when they are in an environment of complete acceptance. Particularly when this environment is different
from their real world, I suggest that there is something that happens to these kids that allows them to experience themselves differently. One of the counselors offered this example:

*I think the same self-confidence that I found that I gained over the years at camp you’ll see it in campers. You’ll have kids that come out and you can tell right away from the start that they’re the quiet kids, they’re a little bit more reserved...back at home they’re probably not the most popular kids ever, and by, you know, mid week once they’ve kind of been pulled in to the group by the other kids and just welcomed with open arms, they really start to thrive and their self confidence is apparent, and you’ll see these kids actually start to become leaders of the group. And even some of the kids who maybe have behavioral problems at home, um, getting a chance to be in an environment that’s so different from what they’re used to, and actually sometimes that extra energy that they don’t know what to do with they can place constructively. They really start to stand out and shine in terms of how they treat other campers. They take on this positive leadership role where they’re really helping the other campers out and it’s really cool to see these kids really...come into their own, and not have to worry about, you know, how cool they look or you know, clothes they’re wearing, or what they need to be doing so that people accept them, and just actually getting a chance to figure out who they think they are, not who other people want them to be.* (Counselor)

Perhaps, like this counselor said, it is that these children – these children who are “poorly adapted to a situation or environment” (Merriam-Webster, 2012), are given space to figure out who they are, not who other people want them to be. They are provided with
space within which they find they fit.

The consequences of “fit” are seemingly endless, for it is from this I suggest that the tangible, perhaps even quantifiable, differences in the children arise. While these differences have been the focus of several research projects (e.g., Balen, Fielding, & Lewis, 1998; Ruffin, Creed, & Jarvis, 1997), I offer that it may be precisely why these presumably measurable constructs (e.g., self-confidence, quality of life) are not only difficult to quantify in this type of environment but also fail to capture the why of the difference. When I first started this research, I felt certain I would, at some point, be discussing the changes in the children, as a result of camp. Indeed, these types of discussions happened frequently in my interviews and are worth discussing (and will be, in Chapter 9). However, the “results” of camp, the changes in the children, are what I now understand as the side effects. I believe the utility, the why, the reason for these changes, to be the space, acceptance, and fit that is experienced at camp.

From Acceptance and Fit to Recognition and Understanding

So when they’re here, it’s not that they’re the [only] family that’s dealing with it [cancer] and friends are all saying “Oh I can’t imagine that, that’s so horrible” right? And they’re talking to people who say that they’ve been through it, they know exactly what they’re feeling and they know exactly what they’ve gone through, they know what they have to look forward to, so families can really talk to each other and relate, and that kind of makes this a really safe environment.

(Counselor)

Camp, never one to discriminate, opens its space of acceptance and fit not only to the children but also the parents. Age and experience, however, position parents
differently in the camp experience, and I believe they experience the acceptance and fit of camp in a different way than their children. For parents, I offer, this comes by way of recognition.

*I mean it’s neat meeting them [other parents] and hearing their stories and being able to share your story and having them understand it, you know. Not having to, you know, explain every little detail. You can say well she went in and got her port accessed and got chemo and they go, oh yeah, ok. Whereas, you know, you say that to somebody on the street and they go, huh?* (Parent)

Many parents told me that one of the best parts (often the best part) of camp, was the relationships they formed with other cancer parents. Because other parents have “been there” and have likely experienced many of the same emotional responses and challenges that accompany the diagnosis of childhood cancer, they are in a unique position to establish a meaningful bond with other cancer parents (Higgins, Santelli, & Turnbull, 1997). Higgins et al. summarized that research indicates support offered from other parents increases parents' acceptance of their situation, increases parents' sense of being able to cope, and offers a unique form of support that would be unlikely to come from any other source. While the bonds created between the parents were strong, I came to understand the formation and subsequent strength of these connections as a form of recognition. Etymologically, the word “recognize” comes from the Latin, *recognoscere*, from re- “again,” and cognoscere – “know,” to recognize is to “know again, acknowledge, recall to mind, examine, certify” (Online Etymology Dictionary, 2012). There was a process of “knowing again” in these families – knowing again the fear, the suffering, the sleepless nights, incessant worry, and all that comes with the diagnosis of
childhood cancer. All of these handmaidens of childhood cancer require no explanation among this group of parents. There is no need to have to explain the severity of a circumstance because other parents at camp understand it intrinsically. They, too, have lived through experiences no one else could understand unless they were in the same situation. Most parents arrive at camp not knowing any other parents, however, in the company of familiar strangers, a closeness quickly ensues. The gap of not knowing someone is filled by the recognition of experience, of “I understand.” Dr. Brene Brown, in her 2012 TED talk entitled “Listening to Shame,” offered that the two most powerful words when we are in struggle are “me too.” “Me too,” she explained, implies empathy, but I offer it implies not just empathy but also recognition.

I extend this one step further – if I look back to what recognition means once again, to “know again,” it is conceivable that there is a recursiveness at play. Parents, I have proposed, recognize (and hence, feel recognized by) other parents who have experienced childhood cancer. However, there is also an element of “knowing again” their own experiences. In other words, they are given an opportunity to “re-know” their experiences of childhood cancer. “Like pulls like. We’re kind of mirrors in a way” (Parent). Mirrors, of course, reflect images, and in this case the images being reflected back to the parents are of their own experiences having a child with cancer. These other parents, mirrors of themselves, can offer an opportunity to come to re-know or know differently how they experience this disease. It is known in the literature that parents of children with cancer often suffer from post-traumatic stress disorder (PTSD) (Bruce, 2006; Lindahl Norberg, Pöder, & von Essen, 2011; Yalug, Tufan, Doksat, & Yaluğ, 2011). Kazak, Boeving, Alderfer, Hwang, and Reilly (2005) demonstrated the high
prevalence of PTSD in their study consisting of 119 mothers and 52 fathers of children with cancer, where all but one parent had PTSD symptoms. Likewise, Alderfer, Cnaan, Annunziato, and Kazak (2005) studied 98 couples who were parents of an adolescent survivor of childhood cancer. The adolescents had completed treatment an average of five years before the study, and although parents' PTSD symptoms were less common than those found in parents during the period of their children's treatment, in the majority of families studied, at least one of the parents had moderate to severe PTSD. Perhaps then, through the opportunity to re-know this experience, to re-visit and re-member, traumatic events and emotions are processed and internalized differently. I offer that it is during this re-visitation that healing occurs, and it is this that is behind the reason so many parents described the importance of connecting with other cancer parents; in recognition, they find healing.

It is important to note while the majority of parents described the importance of connecting with other cancer parents, one parent found it very difficult. These mirrors, I learned, sometimes project back images that are too difficult to see:

_Some people, they take comfort in the fact that, you know, you're not alone in the world, you are not the only person that's gone through this thing. It's, ah, but I'm not there, I don't really want to ah, I don't really want to be reminded. It's still too fresh._ (Parent)

This parent, Don, talked about his “what if” moments – the most terrifying moments during treatment when he knew that there existed the possibility of losing his child. These “what ifs” became paralyzing for him, even causing a period of severe depression at one point. While his child, now recently off treatment, is considered “cured” of
cancer, for this father, his “what ifs,” his deepest darkest moments, are still close by, always hovering within arms reach, like a menacing thunderstorm. He told me about meeting another family at camp whose child was the same age and had the same diagnosis as his child. For this other family, however, it was clear that this would be the last camp their child would attend, as it was evident this child would not survive much longer. For Don, facing that reality, recognizing in that family so much of his own experience, and being confronted by a family whose “what ifs” were coming true, it proved to be overwhelming.

*I was, you know I kind of take it on right, I can’t, I can’t just not feel bad for these people...you know. After imagining it so many times myself what it would be like for us... um, so, ah, so yeah, and then to see it realized in another family...that was...all those what ifs (tearful)....it’s hard. (Don, parent)*

The deepest, darkest spots were described by many of the parents I interviewed, and almost all of them spoke about spending some time there, in those wells of despair. I puzzled over Don’s situation given he was the only parent that described not feeling the relief of connecting with other parents. Other parents, I thought, could offer support for him, and surely he could find relief among these people he shared so much with just by virtue of having a child with the same disease. I will offer that, like anything else, camp is not for everyone. It is not a one size fits all, rather a one size fits most, and perhaps camp did not fit with Don’s way of being. Maturana would call this the way he is structurally determined. An individual’s biopsychosocial – spiritual structure is unique and is the product of the individual’s genetic history as well as his or her history of interactions over time (Maturana & Varela, 1992). In other words, Don’s “structure”
determines how he will respond to environmental influences, and which of those he will experience as meaningful.

I am inclined to think there is another explanation, or another way to understand this. The “deep, dark spots” and “wells of despair” are accurate metaphors for what many parents experience at times throughout the experience of childhood cancer. They fall into a hole, surrounded by darkness, with no understanding of how to climb out. The journey out of the hole, I offer, is comprised of time, healing, adaptation, and sometimes even deliberate intervention (e.g., counseling, anti-depressants). I believe that camp also offers a way out of this hole; it shines a light, throws down a ladder, and extends its hand to help the person out. For Don, it is perhaps his propensity for deep empathy – the way he is structurally determined – coupled with the newness of the experience (his child had only recently finished treatment) that resulted in his reluctance to engage with other parents. Perhaps, Don was simply not ready to connect with other families on an emotional level just yet. It is conceivable that, as time goes on, he may be inclined to do this and could find great support among the other parents. Camp does not force itself on anyone, however, and like a cherished friend, it is there when and if it is needed.

From Recognition to Understanding

There is a subtle yet important difference between recognition and understanding. Where recognition, as established earlier, means to “know again,” to understand is defined as “to grasp the meaning of” (Merriam-Webster, 2012). The word comes from old English understandan, meaning literally to “stand in the midst of” (Etymonline, 2012). I think there is an implied courage when one “stands in the midst of” with another, when one understands. It made me wonder, though, why is it that these parents
“understand” so well? Is it simply having shared experiences or is there something else at play?

I think the thing that we like the most about it is the fact that you can be with other families and you can actually talk over your situations. So you get the idea, cause your friends don’t really understand, your neighbors don’t really understand, so, but when you come together with other families, you know, our situations are all different but we all have a key factor that’s the same. (Parent)

And so they [other cancer parents] understand what you’re going through, the stresses of what you’re going through, you know, the hospital visits and all of that kind of stuff. (Parent)

While they did not term it as such, there is reciprocity to the type of understanding of which these parents spoke. They felt understood, as can be seen in the above quotes, but they were also understanding with respect to the other parents. It seemed to me like the two actions – being both the receiver and giver of understanding – were inseparable. Two parents offered some insight into this when they told me what it is like talking with friends who do not have a child with cancer:

Mother: Some people want to talk about it but I think in general most people really don’t. Cause you know, in all honesty, it’s – especially when it’s friends with children – there’s always that, I don’t know, fear of the unknown, or – so I think it’s hard for them kinda, to reach out to you.

Father: But when you’re first diagnosed I think a lot more people want to know what’s going on. And then – two years down the road, they don’t realize you’re still
in treatment, you’re still, you know – she looks healthy, she’s got way too much energy, so anyone who sees her has no idea she has cancer.

Mother: So if someone says something and you go, oh yeah, you know, Abby is still in treatment or whatever, they go, what? What?

I think it is interesting to look at the concept of understanding in a literal manner. If I choose to “stand in the midst of” with someone, to literally place my body beside theirs, an opening, a space, must necessarily be created for me to do that. This creation or opening of space for another is reminiscent of Maturana’s (1986) definition of love, “opening a space of existence for an other” (p. 59). Perhaps it follows then, that the understanding that occurs among this group of parents is so powerful because it is a form of love. I offer that this is indeed what is happening, and that this special type of understanding these parents have for one another, their courageous ability to “stand in the midst of” with each other, and the space they open for others to stand with them, is a form of love. “And they all love you [at camp], regardless of any circumstance, and no one should have to have a child that has cancer, it’s not fair” (Mother). It is well recognized that contact with other families with similarly affected children is often comforting because they have shared similar experiences (Leonard, 1991) and that parent support groups (which, it may be argued, is informally what is happening at camp) have shown that parents gain increased skills, an increased sense of power and a sense of belonging by connecting with other families in similar situations (Law, King, Stewart, & King, 2002). Camp seems to provide moments and opportunities for these types of interactions to occur that are unlikely to have happened elsewhere, and I believe it is by these families coming together in this environment that the deepest kind of understanding
transpires, the kind of understanding that precipitates healing.

**Concluding Thoughts**

They [cancer families] come out to a place [cancer camp] where there’s a group of people that care specifically about them for no other reason than, I think, that they inspire me, you know. As to what they’re all going through and how they, how well they’re raising their kids and um, it’s just kind of different from regular life. And I think getting that chance to get away from everything they’re used to, and out to a spot where they’re not different, they’re not singled out, and ah, people are just there to look out for them and you know, make sure that they’re just enjoying themselves for once, I think is a really big deal for families. (Counselor)

There is an organic-ness to camp – in the landscape, certainly, but also in what is at play. Naturally occurring interactions, activities, and moments in time where mis is separated from fit, and acceptance, recognition, understanding – all found in abundance – are for some individuals more powerful than any therapeutic intervention. Like the poem in the Tao Te Ching, the greatest utility of camp comes from the empty spaces, for it is in these empty spaces, so perfectly defined by the surrounding structures, that healing occurs.
Chapter Six: Grief – “The Bleached Bones of a Story” (Roy, 2008, p. 33)

Grief likes to appear and disappear as it sees fit. Grief is a trickster. Grief is unpredictable. It hides between our words, refusing to be captured, then comes tumbling out unexpectedly at another time. It would seem then that, on occasion, grief wants to be let out through our stories. In a sense, grief itself wants its burden to be shared. (McConnell, Moules, McCaffrey, & Raffin Bouchal, 2012, p. 6)

McConnell et al.’s (2012) description of grief – likening it, in part, to Hermes, the trickster, and to the interpretiveness of hermeneutics – speaks to the nature of grief I witnessed at camp and in the interviews with families. There was a slippery-ness to this grief – a feeling of it being ever present yet un-graspable, at once pervasive but non-intrusive. It was as if grief understood it was not to be the center of attention, yet, like an uninvited houseguest (Moules, Simonson, Prins, Angus, & Bell, 2004), would not leave. Of all the families who participated in this research only one, the McMahons, was a bereaved family. Grief, however, is not only borne by families who have lost a child; I saw much evidence of anticipatory grief brought about by living in constant fear of losing a child. “You have to “go there” during treatment…or you don’t have to, I did – a lot, ah, think about the worst possible scenario, the what ifs, yeah absolutely” (Parent).

Some families (particularly newly diagnosed families) also experienced grief with respect to the loss of their healthy child as they navigated through having a child with cancer and all the accompanying challenges associated with that diagnosis. This was particularly evident to me when I noticed how even the act of striking up a conversation with a newly diagnosed family often led to tears.
The literature on grief is vast and varied, and while impossible to thoroughly explore in the confines of this chapter, it is worth offering a brief overview of the changing dominant discourse, as I believe some of the “slipperiness” of grief comes from its history. Twentieth century grief research was based on the naturalist paradigm, grounded in quantitative assessment (Silverman & Klass, 1996). Because of the desire to predict, manipulate, and control human reactions, thought and behaviors, typically associated with the scientific paradigm, most of the grief research (and resulting grief therapy) had a prescriptive quality to it. Freud (1917/1957), for example, offered that grief was a cognitive process involving the withdrawal of psychic energy whereby the bereaved detached from the person who had died. The withdrawal of energy from the deceased person was accomplished via several steps, known as “grief work,” and failure to fully detach from the deceased was indicative of unfinished “grief work.” Following Freud, other researchers furthered his ideas through morbid or unresolved grief (Lindemann, 1944), theories of attachment and loss (Bowlby, 1980), and tasks of mourning (Worden, 1982). This traditional approach to grief, as being something one “gets over,” is evident even today: “Some of these bereaved families have been told by the community” it’s a year, get over it” [their grief]. Well no, you don’t have to get over it. (Parent)

Recently however, research and theories on grief have been offered that challenge the traditional thoughts on grief (Attig, 1996; Moules, 1998; Neimeyer, 2001; Silverman & Klass, 1996; Walter, 1996). There has been a paradigm shift from grief being passive and resolvable (e.g., Bowlby, 1980; Freud, 1917/1957), to grief as an experience of relearning the world (Attig, 1996, 2000), continuing bonds with the deceased (Klass,
Silverman, & Nickman, 1996), a lifelong, life changing experience (Moules, 1998), and meaning reconstruction (Neimeyer, 2001). In other words, grief is described not as an activity of resolution, but rather one of accommodation, which is a continual activity that changes over time, but is never completed (Silverman & Klass, 1996).

These two discourses around grief, the traditional and the current, are obviously very different from one another. Their “differentness” is evident today, and perhaps cause for much of the tension that is felt around societal expectations versus individual and family experiences around grief. The new research and theories around grief are exactly that – new – and “undoing” the traditional approaches of grief is an ongoing, lengthy, process. It is, however, this tension between the old and new, this space between what was and what is trying to be, where I find usefulness in understanding the concept of grief at cancer camp. It is in this space where families can understand their grief differently.

**Understanding Differently**

I don’t want to forget that that’s what happened to us, cause he’s not here so, it’s, it’s real and I don’t want to hide it. There’s some families that we have met that don’t want to have anything to do with it [camp] and I...just don’t want to do that. It’s helped my kids grieve, it’s helped us grieve, and, I don’t know, it’s comforting to know that you’re not the only one who has suffered like we have suffered out there. So we can share how we cope, what we do, do we talk about our son, you know, what special memories do we do every year, how do we remember him, how do the kids feel, and do you go to therapy, do you not go to therapy, you know, what do you do? But camp is like our therapy, it’s just
rejuvenating - it brings you together as a family to do something that you would never get to do. (Bereaved parent)

There is an inherent interpretive nature to grief, as it is experienced and understood differently by everyone, as eluded to by the parent in the above quote. Heidegger (1927/1962) suggested that to be human is to interpret, and hermeneutics reminds us that understanding is always interpretation; in fact, understanding is already interpretation, the two inseparable and intimately linked (Gadamer, 1960/1989). It is this concept of the intertwined nature of understanding and interpretation that I wish to bring to the forefront for examination with respect to grief and camp. The McMahon family, their child and brother now 6 years passed, spoke readily about camp being a place that has helped them grieve. More than that, the father spoke to the changing nature of their camp experiences:

I think there becomes a point too where it transitions from where you become a net beneficiary of what happens at camp, to a point where you recognize how much of a strength and a blessing it’s been in your life, so you start to look for ways to reciprocate and give back to it, if that makes sense. (Father)

I have puzzled about this change – from “net beneficiary” to reciprocator, as I felt this change was indicative of something important. It perhaps was representative of the natural progression of grief over the course of six years, but I feel it needs to be highlighted, acknowledged, and exaggerated, in order to understand how grief changes. Collins English Dictionary (2012) defines interpret as “to clarify or explain the meaning of; elucidate.” The word comes from the Latin interpretari, meaning, “to explain, expound, understand” (Etymonline, 2012), while the root of the word, inter, means
between, among, or jointly (eSpindle Learning, 2005). To “understand,” as mentioned in the last chapter, means, “to perceive the meaning of, grasp the idea of, comprehend” (Collins English Dictionary, 2012), and etymologically, “to stand in the midst of” (Online Etymology Dictionary, 2012). Combining these meanings then, to *clarify meaning* and *expound understanding*, while existing *between* that which one endeavors to interpret is what I believe to be at the heart of what happens with grief, at camp. Children and families come to newly clarified meanings – new understandings, while “standing in the midst” of the old and the new – the in-between. They come to interpret and understand their grief differently, because of camp, and that is where the “helping us grieve” comes into play. Camp provides space and opportunities to come to new understandings about their grief, to learn to live alongside it rather than get over it. It is at camp where families learn “grief becomes a permanent, enduring, sometimes relenting, sometimes poignant, but always present part of the life of a person who has lost” (Moules, 1998, p. 148), and I believe when families understand they do not need to “get over” their loved one, they take one step closer to coming to new understandings about how to exist alongside, and with, their grief. The inherent tension between societal pressure to get over grief and their experiences of “not wanting to forget,” has a chance to reconcile, at camp.

**Moments of Magic, Magical Moments**

*I love the campfires that they have every night, but they have a big one the very last night where they do their magical moments, and I love it. I love that we just sit around and reminisce about all the fun things we did, and then singing the songs and watching these counselors that just have, that’s their job is just to make everyone happy, and they come up with these fun songs and they don’t care what*
they look like or how they sound, you know? They’re just there to put a smile on your face...yeah, you got to give it to them, they’re special people. (Parent)

Mine [magical moment] was, this years, um, when we, when there was this giant rain-hail storm we were in the dance music hall and we were with the Sunrise kids and I had so much fun with them cause they were so little, and a whole group of them wanted to play tag and so we were running around tagging each other and switching back and forth. So I really enjoyed that. (Sibling)

I mean, it seems so silly, but what was magical for me was people serving us our meals and taking our plates. Like to me, at camp, everybody pitches in and you do your own kind of thing, so to have that kind of treatment was special for me – partly because just where I’m at, right. (Parent)

“Magical moments” are a special, almost sacred part of the camp experience. No formal definition exists, of course, but one parent described it as, “[a chance to] reflect on the week at camp and what’s your high point – what created the memory, I guess. It’s not always a high point.” These magical moments, I learned, consisted of everything from fun and games, to sharing around a campfire, to the feeling of being cared for. They were sacred moments in time that were highlighted through the ritual of sharing “magical moments” at the campfire. These moments of magic punctuated what was, for many, a perfect week. At first I thought it was poorly named – “magical moments” – given that magic is something not real, an illusion. I was then drawn to Gadamer’s (1960/1989) words: “...in deciphering and interpreting...a miracle takes place: the transformation of
something alien and dead into total contemporaneity and familiarity…that is why the capacity…to understand…is like a secret art, even a magic that frees and binds us” (pp. 163-164). Magic, he suggested, is at play in understanding. Magic, not in the definitive sense of “producing illusions by sleight of hand” (Merriam-Webster, 2012), but rather, I offer, in the etymological sense of “to be able, to have power” (Etymonline, 2012). It is the capacity of being able, having power (magic) that families are able to form a new relationship with grief.

I opened this chapter with a discussion around grief and offered that camp is a way that children and families come to understand their grief differently by way of understanding and interpretation. Magical moments, I suggest, is one of the ways in which this changed understanding occurs, as, in Gadamer’s (1960/1989) words, “something alien is transformed into something familiar” (p. 163). I wish to take this one step further, however, and look at what lies beneath and behind these magical moments. This unassuming, simple practice, I suggest, is part of a larger network of rituals that take place at camp, each of them making up the ritual of camp.

**Camp as Ritual**

*We have a neat ceremony at camp...the families made these little lanterns with a little base out of a chunk of wood off of one of the trees – camp trees – and then we made, um, and then we put popsicle sticks to hold up – makes me cry (getting tearful) – um, put sticks up, and then we did paper and we designed the paper and made it especially for our kids and we floated it at night with a little tea light on it...it was gorgeous. (Parent)*
The luminaries...they took a piece of driftwood, a circle disc of driftwood...they call it tree cookies...and they put a candle in it, but first you have to decorate it and write a memory of your somebody special that has cancer or passed away from cancer, and then you make the luminary around it. You glue it on top and then you put it in the water and you say a prayer or make a wish and you put it off into the pond, and it’s dusk at that point and it’s all lit…it’s really beautiful.

(Parent)

Luminaries, described in the above two quotes, was the activity of this past family camp, in place to honor the children with cancer, both survivors and deceased. Every year, it is something different, families told me, offering the examples of flags and kites they have made for this purpose. Most families spoke of this event – making the luminaries – and for most of these families, even the retelling of the story was an emotional event; it was clear that it had had a profound impact. One of the parents described this as a “ceremony,” however I offer that it is more than a ceremony: it is a ritual. Rituals are present in our everyday lives from birth, to death, and humans have ritualized life events since the beginning of recorded history. The word ritual has a rather mechanistic, routine connotation. Its root word, “rite,” means a ceremonial act or action (Merriam-Webster, 2012), and often is in reference to church or religious ceremonies. Ritual, then, is of, or relating to, rites (Merriam-Webster, 2012), relating to that which is sacred (not unlike magic). It is from this – the association of ritual with that which is sacred – that I frame the remainder of this discussion, specifically with the suggestion of camp as ritual, and ritual, as a way of understanding how it is that children and families come to understand their grief differently, at camp.
Everything at camp – from the activities, to the counselors’ names, to the games and songs at meals and campfires, to creating something in honor of the child with cancer – could be considered a ritual. McCaffrey (2012) wrote,

Ritual is not inevitably mechanistic, but has the dimension of a living process by which the person who enters into the ritual brings it into being through its enactment, and is simultaneously acted upon to shape his or her way of being in-the-world. (p. 4)

This perspective, McCaffrey argued, recognizes the degree to which the mental and the physical are connected. Ritual theories assert that focused interaction is at the heart of all social dynamics, and “rituals generate group emotions that are linked to symbols, forming the basis for beliefs, thinking, morality, and culture” (Summers-Effler, 2006, p. 135). Ritual and emotion are intimately linked, and have been touted as the fundamental mechanism that holds a society together (Durkheim, 1912, cited in Summers-Effler, 2006). Durkheim (1912) described the emotion that is produced from ritual as collective effervescence – a heightened awareness of group membership, as well as a feeling that an outside force (i.e., the ritual) has powerful, even sacred, significance. Ritual is thought to be a window by which people make, and remake, their worlds (Bell, 1992), and Shils (1961) offered that beliefs and rituals are intertwined, as “beliefs could exist without rituals; rituals, however, could not exist without beliefs” (cited in Bell, 1992, p. 7).

Ritual, as Benner (2000) noted, can be an effective healing catalyst. They can provide direction and validation to the search for meaning amidst grief. Through rituals, the grieving are confronted with a new way of knowing, and may come to understand the world differently. It is perhaps, then, because of the collective effervescence (Durkheim,
1912) – the feeling of a powerful, sacred, outside force experienced by these families at camp, these rituals combine to help families make and remake their world (Bell, 1992), and come to new ways of knowing their grief. These rituals, I suggest, help families understand their grief, by bringing it down to a space where they can actually feel and comprehend the enormity of what has happened, and begin to understand differently, forming a new relationship with grief.

**The Opening and Closing of Grief**

Almost every family I interviewed told me about another mother who attended family camp. This woman, Sharon, was a mother to five children, two of whom had passed away (one from cancer, one from SIDS). Sharon had been attending camp with her other children for several years, yet, up until recently, no one knew “her story.”

*Mother:* Well, see, she [Sharon], she’s in a hard place in her life right now. So to her, you know, she just kinda went there [to camp] cause that’s what [her other daughter] wanted to do. But when I said to her “just you’re being here and showing us that, you know, life does go on, and you keep going on, you’re an inspiration to us.” So later she thanked me and she said you know, that really, that really made me feel special that I’m here and I’m doing something that’s powerful for other people.

*Father:* Well this was the first year we’ve gotten her to open up and tell her story. Cause she’s been at every family camp we’ve been at, I think, but not sharing a lot, I guess.
Mother: Yeah not sharing a lot. So, we’re sitting there and I said to her, I said, “Would you mind telling us your story? I mean, we know you lost your daughter”...So...she kinda thought about it.

Father: She didn’t tell us right away – we kept talking about other stuff I think, and then she just opened up.

Mother: Well, see her – she has five children and she’s lost two of them, so the last child died two months after he was born...and then two years after his death [her daughter] was diagnosed with cancer and died. So, you know, for her, she had to deal with his loss and get over that and finally start living again, and then she was faced with this next challenge. So, and then of course, you know, [a lot] of couples going through illnesses with children end up in divorce, well now she’s going through a divorce too. So for her it’s just been one thing after another, and so sometimes she doesn’t feel that, you know, that she has any purpose or...that there’s anything she can contribute anymore.

Many powerful moments of sharing, support, and strength, as illustrated above, were described by parents throughout the interviews. Moments where people took risks, opened themselves up to others, shared their stories of pain and suffering – of grief – and allowed the strength of the group to help them. It is reminiscent of parent support groups, shown to increase skills, sense of power, and a sense of belonging by connecting with other families in similar situations (Law, King, Stewart, & King, 2002), however it is an organic, natural, un-defined type of support versus a prescriptive, interventive type of support one would normally associate with such a group.
The opening up of oneself harkens to the concept of aletheia, described in Chapter 3. Aletheia, “the event of concealment and unconcealment” (Caputo, 1987, p. 115), reminds us that when something is opened, something else is necessarily closed, hidden, or concealed, as in the example offered by Moules (2002) of the opening of the lid of the well. This speaks to grief being an ongoing process, something that one never “gets over,” but learns to live with in different ways. The opening of the well of grief allows for some to escape, yet covers up other parts that are, perhaps, not ready to be exposed to the air. This is cyclical, infinite, and a way in which we can understand the evolving, changing face of grief in families of children with cancer – why it “looks” different over time.

Sometimes, when the “lid” has been opened, it is not as much about what goes out, as what comes in: “Until you really talk to someone who’s child has actually passed away...maybe you think it doesn’t happen?” (Parent). There is a risk parents face, in exposing themselves to others parents of children with cancer. There is a risk that they will be faced with a potential they had perhaps suppressed. I believe this to be a coping mechanism that some parents use to get through the trauma of having a child with cancer. It is a tactic employed to be able to endure versus suffer.

You’re just surviving...you’re just getting through...we had [our child] here, there, and everywhere. My parents were older, they had health issues... we managed, but we didn’t have time as a family unit. We didn’t even realize we had not spent time together as a family in over a year, because of everything we’d been through. [Our child] in the hospital, and all of that happening, we just, we couldn’t. (Parent)
Chemo schedules, and you’re worried about your kid surviving and most of these families are young, very young parents, working, so parents have to quit work. Now you’re trying to manage on one income, you got to do what you got to do with your other kids. Lots come to Edmonton, there’s one family, the mom had to come to Edmonton for two years, split from her family up in [the North]...how do you do that? Well, you’re relying on extended family, friends, grandparents whatever, to manage the kids left at home. Well, one parent’s working and the other parent’s here with the kid. It’s huge, how – so much to take in. (Parent)

Morse and Carter (1996) differentiated between the concepts of enduring and suffering. They described three types of endurance: enduring to survive – occurring in response to an extraordinary physiological threat; enduring to live – when the individual experiences significant psychological threat and finds him/herself in untenable circumstances for which there is no apparent alternative, reprieve, or release; and enduring to die – the psychological and physiological threat occurring when the individual is “holding on” until bringing closure to their life. The essential characteristic of all types of endurance, they offered, is the absence of emotion. When enduring, individuals are said to be “holding themselves together,” consciously suppressing emotions to maintain control, focusing only on the present. It is an important, adaptive behavior allowing individuals to get through difficult circumstances. It is conceivable that for some parents (for example, Don, described in Chapter 5, who was trepidatious about sharing with other parents), the opening of the lid of the well moves them out of the realm of enduring and into the realm of suffering. Suffering is said to be the emotional
response to enduring, and manifests itself in intense emotion, and a comparative focus on the past, present, or future (Morse & Carter, 1996). When the individual is ready and able to acknowledge that which is being endured, he/she is said to move into suffering. As the relationship between suffering and enduring is not linear, individuals may briefly experience suffering, then quickly return to the state of enduring. This is similar to aletheia, and the concept of when something is opened, something else is covered up; in this case, demonstrated by the back and forth-ness of enduring and suffering.

Suffering, an inescapable human emotion, can be an uncomfortable, even torturous state within which to exist. I suggest that, for some parents, the chance to open their well of grief and allow the burden of their suffering to be shared with others, softens it somewhat. It roughs out the edges and lightens the load of what can be an unbearable weight. Sharing the suffering with others, if one is ready, can allow for the individuals to understand their grief, their suffering, differently.

Concluding Thoughts

Perhaps it’s true that things can change in a day. That a few dozen hours can affect the outcome of whole lifetimes. And that when they do, those few dozen hours, like the salvaged remains of a burned house – the charred clock, the singed photograph, the scorched furniture – must be resurrected from the ruins and examined. Preserved. Accounted for. Little events, ordinary things, smashed and reconstituted. Imbued with new meaning. Suddenly they become the bleached bones of a story. (Roy, 2008, pp. 32-33)

Grief, I have proposed, is something with which families and children have an ongoing, evolving relationship. Through its magical moments and rituals, cancer camp is
a means by which this relationship evolves, and families are able to incorporate grief into their lives, rather than feel it is something they need to overcome. The concepts of aletheia, endurance, and suffering, offer a way to think about this change taking place, and how individuals are able, over time, to come to a place of healing. It is perhaps for these reasons together that, at camp, “things can change in day…and affect the outcome of whole lifetimes” (Roy, 2008, p. 32), and grief can become the bleached bones of the story.
Chapter Seven: The Stories of Cancer – From Glitter to Gratitude

Children never get to the point,

They surround it.

The importance of the point

Is the landscape of it.

You begin discussing

“The Rainfall of Vancouver Island”

And somebody has an uncle who lives there.

And there is an uncle in Alberta

Who has a zillion cows,

Some chickens, and a horse

(We get to feed the chickens

and ride the horse),

Which brings us to an uncle

In Saskatchewan, who has a house where

Deer pass the kitchen window

Every morning (he take us out

And shows us where they go).

If there were no uncles on Vancouver Island

It would never rain there.


As I write this dissertation, my daughters are three and fourteen years old.

Despite their age difference, they are not as different as it might seem, particularly when
it comes to telling stories. I marvel at the roundabout way in which words fall out of their mouths, saying nothing and everything at once. I have learned the art, as every parent must, of teasing out “the point” of their stories, often hidden among the debris of half-sentences, and distracted observations. Stevens’ (1981) poem, particularly the first four lines, has had me pause to consider “points” and “landscapes,” of stories. With children, “the importance of the point is the landscape of it,” and I am brought back to my feelings of anxiety I had during my research interviews, as I felt that most children were “only” telling me stories, usually about what they did, not about how they felt. Try as I might, I was unable to get the kids to engage in, what I considered, “meaningful” conversation, with powerful quotes that would end up in my dissertation. I realize now, I was neglecting the landscapes of their stories. Their points were in the landscapes of their stories, and it was my error to have expected anything different.

Storytelling is said to have been around since the development of language. It has been used for centuries as a vehicle of communication and a way of passing wisdom along through the generations (Koch, 1998). “Stories are how we learn. The progenitors of the world's religions understood this, handing down our great myths and legends from generation to generation” (Mooney & Holt, 1996, p. 7). They are an important form of communication through which individuals, communities, and society conveys important messages, entertainment, knowledge, and experience to others (Bowles, 1995). Stories assist with reaffirming our lives and experiences, helping us connect with our inner selves and others (Atkinson, 2002).

“Stories” and “narratives” are often used interchangeably in the literature (Riley & Hawe, 2005). People lead storied lives (Connelly & Clandinin, 1990), and Frank
(2000) suggested that people convey and tell stories rather than narratives. Wiltshire (1995) defined stories as personal experiences, informally and subjectively recounted, while Rubin and Rubin (2005) offered that stories are purposeful, and have the ability to change. Narratives, conversely, have been defined as being more structured and formal (Wiltshire, 1995), a partial description of a larger story (Rubin & Rubin, 2005), and, with respect to research, structured and formal accounts containing researcher additions and omissions (East, Jackson, O’Brien, & Peters, 2010). While I appreciate the distinction between the terms, for the purposes of this discussion, I have chosen to use the term story, as I believe it best speaks to the nature of what it is children and families are doing – they are telling their stories.

The Stories of the Children: Feeding Chickens and Riding Horses

Perhaps most fittingly, it is appropriate that I begin this part of the discussion by way of a story, of sorts. When I interviewed the McMahon family the youngest child, Christina, nine years old, sat quietly at the end of the couch near her dad. I was aware of her watching me – constantly – but she said little, usually being drowned out by her more gregarious older sisters and brother. She was wearing her camp shirt signed by fellow campers and counselors, and when I commented on it she beamed with pride, clearly happy I noticed. Christina contributed little for the first two-thirds of the interview, and I got the impression she was happy to sit on the sidelines. Something happened, though, toward the end, and Christina all of a sudden dominated the interview. As I reviewed the transcript, I counted thirteen times she spoke in the last third of the interview, versus two times in the first two thirds. I offer the following section of transcript not for the content, specifically, but more for the “dynamic” of what was happening:
Christina: Also one of the things that I really liked was um, we were doing these super skills and I was in the studio and I learned a different way of finger-netting and um, these other people wanted me to show them how to do it, then all the people wanted to do it.

CML (Interviewer): So you got to teach everybody how to do it?

Christina: Yeah, and well, I told one of the counselors how to do it and she, like, some people from my group, we added all ours together.

Older sister: Tell her how long it was when you added it together.

Christina: Um, well mine, it was like a square and I had different colors, red, purple, blue, and I could jump over it, and then a lot of people wanted me to make, help them make some, and then like, they had fun.

CML: So you got pretty good at that!

Older sister: They like, linked all their finger-nettings together, it was from one goal post to the other goal post, it was long.

Christina: (laughing) Yeah, it was long enough that like, a lot of people liked it, they had fun. And her group (pointing to older sister), they were doing face painting and they liked it.

Older sister: Every day we would have a new theme so on the day of her show and tell we would have Diva faces...glitter everywhere...and we had flowers, we did a tiger, we did an old man face...

Christina: Um, there were other super skill groups like...(everyone starts talking at once, can’t make anything out).
Christina was engaged with me and telling me a story, her story, of something she did at camp. I, frankly, had no idea what she was describing at the time (it took me listening, and re-listening to the recording several times to understand what she was talking about). She talked quickly, her body leaning toward me, her eyes locked on mine, willing me to stay with her story. The kind of story nine year olds tell, with ambiguous beginnings, middles, and endings – the kind of story you need to “peripherally” listen to, because you lose the point when you listen straight on. The “point,” I realized, was about how she took a leadership role in her group, and taught others a skill she had mastered. The point for her, however, lay in the landscape of the story – the finger-netting, the colors, the fact that everyone had fun – not at all about mastery and leadership.

Both of Christina’s parents commented on her sudden talkativeness during the interview:

*Christina: Some of these people, like, I’ve had the same leader for two years, for Sparks and Kindling 1, last year and this year, and we did the same thing, and well, I remember we did the scavenger hunt and we all had a lot of fun, like, we traded people – well, only my group and another group, and like, this one time it said “find a robot watch” and it was Rocket’s birthday that day, and Orca called over Rocket and so we started singing happy birthday, and then we noticed the robot watch and were like, “Oh, there it is!” And then the climbing wall, the giant swing, the zip-line, I hadn’t done the giant swing or zip line yet and it was a really good experience for me.*

*Father: You’re just a chatty Cathy, I like this!*

*Mother: I’ve never heard you talk so much!*
Her talkativeness was further punctuated after the interview was over and Christina and her mother were showing me pictures and mementos of Tanner, their child and brother who had passed away. Christina remained very talkative, telling me stories about how she would accompany her brother when he needed painful procedures, and how “they didn’t let anyone into the room, but they let me in because they knew I could help calm him down.” At one point, her mother said, “This is so unlike her. She never talks this much!” and I wondered about this for many days afterwards. Something had happened there – something was going on – and I was reminded of Gadamer’s words, “understanding begins when something addresses us,” (Gadamer, 1960/1989, p. 299), but, as Jardine (2012) pointed out, “it only begins there” (p. 4). In order to understand what is happening when we tell our stories, it is important to look beyond just the words. The stories we tell are not to say what we know, but to find out what we know, and in telling stories, “we try to make sense of life, like we try to make sense of a text when we interpret it” (Widdershoven, 1993, p. 9). Stories of illness (in Christina’s case, of her brother’s illness) help make sense and give meaning to dramatic and confusing times of life (Abma, 2005; Bosticco & Thompson, 2005).

We are our stories, and Abram (2010) reminded us that, historically, “spoken stories were the living encyclopedias of our oral ancestors” (p. 10), often carrying practical knowledge like instructions for the hunting of various animals, which plants were good to eat and which were poisonous, and how to construct a winter shelter. We come from a tradition of storytelling that served a practical purpose of how to live in the world. Our stories today, though not often practical in the sense of how to construct winter shelter or avoid consuming poisonous plants, remain practical in the sense of
making sense and increasing understanding of personal experiences (Frank, 1995), and promoting awareness of, and reflection on, life circumstances (Carlick & Biley, 2004). They still teach us how to live in the world, particularly when faced with the task of making sense of illness or tragedy.

The process of telling a story is interesting, given the fallibility of memory is such that people remember a story the way they wish to remember it (Kitzinger, 2004). Stories are subjective, said Sandelowski (1993), and they are influenced by environments, social situations, changing perspectives, the audience, and the purpose of relating the story. When telling a story, we make choices about what to include, highlighting some events and omitting others (Bauman, 2004). It is precisely this, however, the subjectivity, inclusion or exclusion of events, and the personal choices that are made in the telling, that makes it a story. I heard stories from children during my interviews but even more so at camp. On the way to and from activities, during activities, eating meals, and during free time, I heard nothing but stories. Children telling each other stories, telling the counselors stories, telling me stories – the stories filled silences and empty spaces. At times it was overwhelming and consuming for my quiet, adult nature, but as I reflect on it now I can see how this normal, unassuming occurrence served a very important role. Like Christina, when these children told their stories, they were making sense of their lives. Their stories were helping them process, understand, and deal with profound events – the kind of events, like being diagnosed with cancer as a child or losing a brother to cancer, that are difficult to make sense of, even for adults. I am not suggesting that their stories were always serious or even about cancer most of the time; I believe, however, that like Christina, sometimes the landscapes of their stories, the hidden points
– best seen by sideways glances – were what helped them reflect on, and make sense of, childhood cancer. Camp provided innumerable opportunities, spaces, and places in which the children could fill with their stories, and it was as if, by the end, they had found a new way to live in the world.

The storyteller does not stand outside of all stories as the purveyor who then decides what information to embody in a story but stands in the story as its teller. The story must be conceived as a recollection of community, a recollection of belonging together. Everyone, teacher and child, has a story to tell. The importance of the storytelling analogy is that it contains in itself the self-recognition of being an analogy. Of course, it must do this because, after all, what is a story but an analogy – an analogue which gathers for us, teacher and children, the most significant and true elements of our being in the world. (Jardine & Clandinin, 1987, p. 480)

The Stories of Parents: “Even the Earth Trembles Now and Again” (Sogyal Rinpoche, 1993)

Storytelling, or sharing of stories, does not just take place among the children, at camp. In chapter 5, I discussed the supportive and valuable role parents have with one another, and suggested that recognition and understanding are ways in which we might understand this. Sharing of stories is another way in which parents too, benefit from the camp experience. I wish to tilt the angle of this lens, just slightly, and focus not as much on the stories of the parents, per se, rather on underlying message I heard from parents.

*I guess for me, points of gratefulness too, just that recognition of, and I don’t know how many times I said it, but the willingness of people to sacrifice their
money, their time, whatever, so that people like us can have a safe place to go. I don’t know how many times I cried when I was there [camp] (crying). And, you know, I went up to [the people who spoke at the] grand opening and I just I thanked them, cause I said, you know what, like, so many people give of themselves and they’ve never been through it. And I guess I find that always an amazing thing that people are willing to do it. But I’m also very, very grateful because you know, with what we’ve been through, some of these experiences, we would’ve never been able to have without that. We just wouldn’t, and so you know, there’s definitely a huge element of gratefulness (teary). (Parent)

There was an underlying thread of profound gratitude among the parents of the children with cancer. This gratitude, I surmise, was about many things: for the camp itself, for their children being alive and able to participate, and even for the break from their daily lives and routines. It is the kind of gratitude that is possible, I believe, only when one is able to be truly present in a moment, aware of the finitude of life. Tibetan Buddhism calls this concept “impermanence,” and its doctrines teach of the value of impermanence, and the importance of accepting the impermanence of our lives.

Ask yourself these two questions: Do I remember at every moment that I am dying, and everyone and everything else is, and so treat all beings at all times with compassion? Has my understanding of death and impermanence become so keen and so urgent that I am devoting every second to the pursuit of enlightenment? If you can answer ‘yes' to both of these, then you have really understood impermanence. (Sogyal Rinpoche, 1993, p. 27)
I propose that many parents of children with cancer have a sense of impermanence that fills their lives. Even in the face of statistics, claiming (in some cases) greater than 80% survival rates, once parents hear the words “your child has cancer,” they are forced to face and consider their child’s mortality. Impermanence is not a concept only for parents of children with cancer, of course. We are all aware, to varying degrees, that our lives are limited and that nothing, in a sense, is forever. However, in this age of advanced medical technology, our youth-obsessed Western culture is not inclined to often consider this. To acknowledge impermanence is to acknowledge death, and it is well documented that we, as a culture, do not do this readily. Bayer (2004) reported that, in the United States, between the period of 1997 to 2001, cosmetic procedures increased 311% for women, and 256% for men. Western culture, Bayer surmised, is doing nothing to dispel fears of aging and death; if anything it is promoting and perpetuating it by continuously and unrelentingly placing such high value on the retention of youth. Likewise, Berger (2008) noted that youth is not only associated with beauty and illusory perfection, but also with vitality, defined as “how healthy and energetic – physically, intellectually, and socially – an individual feels” (p. 546). Considering this definition of vitality, it is not difficult to see why one would fear aging and death in a culture that idolizes youth.

These parents, I believe, are acutely aware of the impermanence of their child, and it is perhaps this heightened sense of impermanence and awareness of the fragility of life, that causes gratitude to the degree in which I experienced it in them.

*In our journey, I haven’t had a lot of connection with other people who had kids with cancer so it was pretty neat for me to be able to talk to people and, and have that um, commonality. Yeah. And camp itself – I could go on and on – just, the*
way we were treated, the quality of the counselors, the staff. The only, the only thing I can equate it to is a mini version of, you know, Disneyland, or that kind of thing – Disney’s motto of “the happiest place on earth.” I mean that’s how, that’s how they are, and ah, yeah, again when you’ve been through hard stuff, being treated like that is just – I can’t say I was shocked, but it sure felt good.

(Parent)

Knowing that something will not last can be of benefit. When something is pleasant, knowing it will not last helps us to not take it for granted, be present with it, and appreciate it in the moment. When something is unpleasant, knowing that it will not last can make it more bearable. It can help us to appreciate the good, having experienced the bad. In the Buddhist tradition, impermanence is one of the essential doctrines, or three marks of existence. It is the practice of recognizing that everything changes, and nothing has a fixed identity, or permanence. Those who subscribe to the Buddhist doctrine strive to incorporate it into their lives, using it as an instrument to penetrate deeply into reality, understanding that reality is never static, but is dynamic throughout.

The realization of impermanence is paradoxically the only thing we can hold onto, perhaps our only lasting possession. It is like the sky, or the earth. No matter how much everything around us may change or collapse, they endure. Say we go through a shattering emotional crisis…our whole life seems to be disintegrating…our husband or wife suddenly leaves us without warning. The earth is still there; the sky is still there. Of course, even the earth trembles now and again, just to remind us we cannot take anything for granted. (Sogyal Rinpoche, 1993, pp. 25-26)
Parents, I have suggested, are acutely aware (either consciously or subconsciously) of the impermanence that affects us all, but for most is a concept ranging from uncomfortable to terrifying. Hand in hand with this awareness, I suggest, comes gratitude, albeit often at a deeply subconscious level. Johnson (2009) suggested that impermanence can inspire gratitude by reminding us that we are part of a larger whole. It reminds us to live life fully, each moment never to be duplicated, and never knowing when the end of our lives may be. Johnson suggested that impermanence can remind us of the absurdity of life, pushing us to find a healthy balance between intentional living and not taking life too seriously. I want to be careful not to romanticize this notion too much. I am not suggesting that parents of children with cancer just accept what has happened with a “whatever happens, happens” kind of approach. On the contrary, I believe that the perspective of impermanence and the feelings of gratitude seep in through the cracks, perhaps, like as Cohen (1992) suggested, “There is a crack in everything, that's how the light gets in.” Camp cracks the shell of fear around parents of children with cancer, allowing the light, the gratitude, to get in, and to help unlock emotions that may, perhaps, have been locked away from the moment of diagnosis. Quite simply, it feels better to be grateful than to have no gratitude. Camp offers the opportunity to feel gratitude and express gratefulness. Being grateful of something is indicative of a certain level of emotional health, of healing. When one is consumed with fear or anger, or full of stress, it is impossible to make room for gratitude. It is perhaps the ability to feel grateful for something, that lets a parent know they can get through the nightmare of childhood cancer.
Gratitude unlocks the fullness of life. It turns what we have into enough, and more. It turns denial into acceptance, chaos into order, confusion into clarity...It turns problems into gifts, failures into success, the unexpected into perfect timing, and mistakes into important events. Gratitude makes sense of our past, brings peace for today and creates a vision for tomorrow. (Beattie, 2000, p. 9)

**Concluding Thoughts**

*O body swayed to music,*

*O brightening glance,*

*How can we tell the dancer from the dance?* (Yeats, 1928)

We are our stories, and like the dancer and the dance, in Yeats’ poem, it is difficult to differentiate ourselves from our stories. Our stories link our past to our present (France & Uhlin, 2006), and allow us to reflect on our world (Frank, 2000; King, 2003). Stories allow us to assert meaning on events, “so, one may review past events through narration and say, ‘Oh now I see,' as if it were the first time” (Churchill & Churchill, 1982, p. 73). The telling of stories has been demonstrated to increase resilience (Dean, 1995), insight (Jackson & Mannix, 2003), and hardiness (Leseho & Block, 2005).

We live by stories, we also live in them. One way or another we are living the stories planted – knowingly or unknowingly – in ourselves. We live stories that either give our lives meaning or negate it with meaninglessness. If we change the stories we live by, quite possibly we change our lives. (Okri, 1997, p. 46).
It is, perhaps, one of the greatest gifts that camp offers the children with cancer and their families – the space, time, and opportunity to tell their stories and to come to understand the meaning of childhood cancer differently.
Chapter Eight: Community as *Sensus Communis*

Just as it is impossible to separate ourselves from our stories, so too it is impossible to separate ourselves from the communities within which we live. I speak, of course, not in the literal sense of leaving a physical location and, thus, a community, but rather in the sense of it being impossible to separate from the traditions, history, and culture of the communities within which our lives are housed. We belong to many communities throughout the course of our lifetimes, some defined by physical boundaries like the communities in which we live, and others defined by shared interests or circumstances. Community is a concept or model – something we cannot physically touch or view in its entirety – and is defined as “a unified body of individuals” (Merriam-Webster, 2012). Often, when we speak of communities, we speak of having a sense of community, comprised of membership, influence, integration and fulfillment of needs, and shared emotional connection (McMillan & Chavis, 1986). Central to the idea of community, is the concept of belonging to something. The community of childhood cancer – individuals and families who share the common denominator of childhood cancer – is a community no one enters willingly, yet once inside, appears to offer a profound sense of belonging. This sense of belonging has been discussed in the literature in the context of minority identity (e.g., Koefoed & Simonsen, 2011; Lee & Brotman, 2011; Peplau, Fingerhut, Grant, Wittig, & Ghavami, 2011). Being in a minority, such as the community of families with childhood cancer, can be a marginalizing experience, but also one offering a feeling of protectiveness and identity reinforcing.

*It’s different for everybody but for me, I think the experience of being in a place where people are all experiencing, or have experienced, the same thing...and the*
support that gives, especially for people who don’t ever get a break...to be in a place where everybody’s experienced the same or similar, and are supporting one another and being able to just be who you are. (Parent)

Gadamer (1960/1989) spoke of sensus communis, its literal translation from Latin meaning “common sense,” however not in the regular, every day use of the phrase. Sensus communis, according to Gadamer, relates to the general sense – the “common” sense – of the community. It is a common sense not only because it is widely accepted, but also because it is genuinely, authentically, shared by a community (Gelfert, 2006). “The main thing for our purposes is that here sensus communis obviously does not mean only that general faculty in all men but the sense that founds community…hence, developing this communal sense is of decisive importance for living” (Gadamer, 1960/1989, p. 21). Sensus communis can help us contextualize and understand in different ways, and is rooted in a common way of being. It speaks of connectedness to others and a deep sense of belonging.

I believe one of the ways we might understand the profound connections and support that families offer one another simply by virtue of a shared diagnosis is through sensus communis. These families share a “common” sense with one another – a sense only acquired by those who share the experience of having a child with cancer. There is a privacy to this sense – even I, for example, having worked closely with these children and families for many years, can never share in this “common” sense. Knowledge exists within the sensus communis that cannot be taught. As much as I would like to think I know about this experience, I can never really know it, unless I have lived it.

One of the dad’s said, “I can’t take anymore time off work so I could only come
out for a couple days, cause you know, being off for a year” and I said “Yeah,” and he goes, “People here get that! My family doesn’t get that!” And he kinda walks away and I’m laughing to myself, cause it was true, you know, we do get that, because all of a sudden you’re not able to work, you’re not able to do anything. (Parent)

People don’t show sympathy for you, they show empathy [at camp]. They understand – you don’t have to explain…and so you get into camp, you don’t have to explain chemo, you don’t have to explain radiation…cause you’ve got this experience bottled up and who can you talk to? Well, you know what, cancer parents you can tell anything (laughs), we’ve seen everything – or feel like we have! (Parent)

It struck me that there was a sense of relief among these families, at belonging to this community – the kind of relief that helps to shoulder the heavy weight of the burden of this disease, and that offers a break from the fear and despair so often experienced, particularly in families newly diagnosed. This sense of community, belonging – the sensus communis – is fostered by children’s cancer camps. Camp brings these families together into its community, the physical community of camp, defined in the traditional sense of the word by its landscape and natural boundaries. Then, like good hermeneutic work (Moules, 2012), it disappears into the background and allows for the sensus communis to form. For many families, camp is the first time they are exposed to other cancer families and often, up until that point, have felt very alone and isolated.

And you know, the thing is, sometimes I think when you’re in it and feel alone, yeah you go to the hospital and you see everybody else going through their stuff
and you realize that you’re not the only one, but you’re not there to converse on a personal level, you know? And so yeah, it’s probably few and far between conversations in the years since treatment that I’ve had this, been able to have these kinds of conversations with parents. (Parent)

A Safe Place to Be

Part of the sensus communis in this community is comprised of a concern for safety. In chapter 1, I detailed some of the physical and practical concerns for these children with cancer that necessitates the need for a camp suited specifically for their unique needs and challenges. This safety concern, I learned, is one of the elements that falls under the umbrella of “you cannot understand it unless you have lived it” and, without exception, every parent I spoke to discussed their concerns around safety.

I guess one big thing too, was the um, having a safe place where there isn’t sickness or illness. Making sure that nobody comes to camp sick because of the health concerns, and, you know, [immune suppressed] systems kids have to deal with, you know…and when they’re on medication or they have to be in the nursing station, or whatever, for three or four hours a day, um, you can’t do that anywhere else. So the specific needs are addressed and cared for – a lot of those kids wouldn’t be able to go to any other camp. (Parent)

It’s a very safe environment…a testimony to how safe an environment that the medical profession itself perceives the camp to be, that they understand the circumstances, they understand the limitations of the kids, they understand how to help them experience things, but yet in a safe and ah, I guess you could say,
controlled environment, as much as you can have it, right. And still giving them that chance to be a kid but not, not forgetting the fact they are kids with cancer.

It’s a unique world. It needs that targeted attention as opposed to a more generic camp, right – which certainly has value and is altruistic in nature – but doesn’t have that added level of understanding and care associated with it. (Parent)

Safety is a concept that, like play, is often taken for granted or not thought about with any depth, until it is missing. I find I often understand these concepts best by exploring their opposite – in this case, understanding safety by looking at what it is like to feel unsafe.

Thankfully, there are not many times in my life when I have truly felt unsafe. I recall a Tuk-Tuk ride (similar to a rickshaw, used as a taxi) through downtown Bangkok several years ago, where the extreme speed, erratic driving, and (seemingly, to me) lack of rules governing driving behavior, had me sure something disastrous would happen. I had no control over the situation, and felt completely unsafe. Feeling safe implies a sense of control over the environment; when we are in control of “things” we are more inclined to feel secure than when we have no control. Once a child is diagnosed with cancer, parents, in many ways, must relinquish much of their control with respect to their child. Treatment, schedules, side-effects, along with innumerable aspects of daily life are no longer in a parent’s control, and I suggest that this leads to an immeasurable sense of feeling unsafe. While parents spoke about the safety needed for their child (at camp), I suggest that the safety to which they were referring, was also for themselves. Camp provided the opportunity to experience safety without the stranglehold, often obsessive preoccupation, of concern for their child. Parents were able to feel in control, knowing that camp is structured in such a way as to (as much as possible) ensure the safety of the
children. It is paradoxical because by regaining a sense of control – of safety – from camp, they were able to relinquish some of the control with respect to their children. In other words, they are given a break from constantly thinking about their child’s safety.

So, you know, they were doing their thing, something happened and the rocks got thrown, Matthew had a fit cause he had put them all in a row, and you know, everything has to be linear with him, and he went launching after this little boy.

And this girl [referring to a counselor], who you know, is young, really, stepped in, calmly stopped it, turned the situation around, and before I could get two feet she had it under control, she'd calmed it down, and she had directed him to something else. And that made the whole week for me, cause at his school, it took eight months to get them to understand him, and it took her an hour. (Parent)

There was another kind of safety discussed in an interview with a mother, Linda. She and her family had escaped from a country wrought with turmoil, where she feared daily for the safety of her three children. When the family escaped, her middle child had already been diagnosed with cancer, and she did not know if her daughter would arrive alive, in Canada.

My husband, he can’t work because the people try to kill him. They say, “your kids go to school, we will kill them,”...The doctors say, “you have to go to Canada, it’s the only way Daisy will survive, she has to go and see fast another physician there.” But she’s so sick and I’m so scared to travel to here. When we get to Calgary, Daisy so sick, so sick...go to ICU...I no speak any English, I have

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4 As this mother speaks English as a second language, I have edited these sections of the transcript in order to improve the readability. I have made great efforts to maintain accuracy to her story, however, and to make sure it is still her voice coming through.
only two dollar, it’s snowing and I never see snow before…and Daisy say to me, “speak to the doctors and tell them I going to die tonight.” I’m so scared, and say, “oh no” (crying)...and I tell her “I’m so tired, Daisy....please, can you wait for me a little bit more, until I rest?”

Safety, at camp, I learned, sometimes goes beyond the specialized training of the staff, and the attendance to the immunocompromised status of some of the children. For this mother, the safety of camp was about literally knowing her children would not be shot. For her, camp punctuates the fact that they are now safe, as a family, and that they now live in a country that is not overrun by the drug industry, where they have access to medical care, and where they have control over their lives – where they are safe.

I feel...(whispers) like, a peace, at camp. When I go out there, I feel like I don’t want to go back...want to stay. I feel my family has safety place to be, at camp, and I feel like my problem has gone. For a while. I feel so rest and I enjoy it all the time when I go there.

Linda spoke many times during the interview about peace, and feeling at peace, at camp. I struggled, at times, to maintain my composure, as I absorbed all that she told me about the circumstances from which she came, and her tumultuous arrival in Canada, coming unspeakably close to losing her daughter, asking her to wait for her to rest, before she died. It struck me, how this little entity called cancer camp, is so much more than just a camp, and how it represents freedom, and safety – real safety – as in, “I am in no danger of being killed,” kind of safety. It is so many things for so many people, and to think of it as “just a camp” is to grossly underestimate its value. It represents hope, recovery, and symbolizes the continuance of life and the promise of new tomorrows, for some. It is a
place of healing, kinship, learning, and change, and a place of new understandings, and
new beginnings. It is a place of throwing water balloons on counselors, laughing around
campfires, getting mosquito bites on your arms, and dirt under your nails. It is this kind
of experience and understanding that contributes to the sensus communis of this
community.

**Heeding the Call of the Other**

Being in a community necessarily implies one is not alone. This brings to mind
Levinas’ (1969/1980) concept of the “Other,” referring to a person Other than one’s self.
The Other, according to Levinas, is identified as “different,” and an encounter with
another, is a privileged occurrence. A part of how we understand ourselves, said
Levinas, is determined by how we define the other, as many of the roles we construct for
ourselves are done so in relation to the other. The moment we encounter the face of
another – Levinas (1985) described this as the face-to-face encounter with the Other – is
the moment we enter the grip of another, and are beholden to an ethical responsibility:

> Access to the face is straightaway ethical…There is first the very uprightness of
> the face, its upright exposure, without defense. The skin of the face is that which
> stays most naked, most destitute. It is the most naked, though with a decent
> nudity. It is the most destitute also: there is an essential poverty in the face; the
> proof of this is that one tries to mask this poverty by putting on poses, by taking
> on a countenance. (p. 85)

Recognizing the Other begins with the opening of the self in the face-to-face encounter,
and an understanding that the Other needs something from you. It is an inescapable call,
connected to recognizing the suffering of another, and opening of the self so as to put
oneself into a place of vulnerability. This vulnerability, according to Levinas (1969/1980), is the starting point for the responsibility, or ethic, we feel toward another human being. A call to ethics in relationship begins with this interruption of self, by self (Levinas, 1969/1980).

Children, particularly siblings of children with cancer, were presented with many opportunities at camp during which they were confronted with “otherness.”

Mother: Michael [eight year old sibling] had an eye-opener this year, he was telling us about it.

CML (Interviewer): What was that?

Mother: Scars. The scars that some of the kids have. Because he sees Abby, because she has ALL [leukemia], she just has one little scar and a bump, so to him, it’s all neat and tidy. But when he sees some of these other kids and their scars are...like all over, in different spots...

Father: You know, he said, “One guy had a big scar across his belly and stuff”...

CML: And how does he – did he – process that? What does he think of that?

Mother: I’m not sure...he just mentioned it and wanted to know why that would be and we told him well, because kids have cancer in all different kinds of spots so their surgery would be different, and he kinda just processed it but I don’t think he [had] really thought about different types of cancer.

Father: But he’s very accepting of it, I think because of going out there [camp]. He’s met kids, you know, who’re not quite confined to a wheelchair, but pretty close, you know, and he doesn’t discriminate against them. I mean he just accepts them, as...kids.
I believe one way to understand how children process these kinds of encounters with other children, so physically or cognitively different from themselves, is through understanding the concept of the Other. Kearney (2003) argued that, until we recognize ourselves in the Other and understand that the Other resides within ourselves, we cannot understand how our most basic fears and desires manifest themselves in the world, and how we can learn to live with them. This seems like a complex, philosophical thought with respect to children, but I offer that there is simplicity to it. These children are presented with moments in which they realize that kids with scars, missing limbs, Down syndrome, and other anomalies, are really not that different from themselves. On some level, they are aware of the familiarity and strangeness of the Other (Levinas, 1969/1980), and are confronted with moments in which responsibility takes them over, and they recognize the call of the Other to accept their differentness, their otherness. It is perhaps the very emergence and enactment of the “common” sense that brings forth the Other, and offers an inescapable realization of otherness. Another parent offered this explanation:

But, you know, if you’re in a school setting where there’s 300 [kids] – or the child in the wheelchair is one of 300 kids and you don’t get the one on one, but out there [at camp] you get small group exposure to all these kids [referring to kids in wheelchairs, or other visually “different” kids] and you realize they’re still normal kids if they’re in a wheel chair, or they don’t have a leg, or if they don’t have hair, or have a big scar across their chest. You know, so it gives them [siblings] – yeah, exposure is probably the best way to say it. And there was – there’s always been somebody running around without a leg! (Parent)
By virtue of repeated exposure to “otherness,” at camp, children gain awareness, an ethical responsibility of sorts, for the Other. This is why camp is not just camp. This is one of the invisible, nameless, intangible things that happens, that we call “building character,” “compassion,” or “tolerance,” and, while aptly named in some respects, are the side effects of this recognition of the Other. A mother described how this capacity, this sense of humanity, manifests and extends beyond camp:

Before we went to camp, Molly [the sibling of the child with cancer] was in [preschool], and she made a comment that one of the other little boys, she didn’t like him, because he tried to hug her and he was different. And I was like, “WHOA, back up the bus! We don’t talk like that, we don’t use those mean words, we don’t refer to that, where did you learn these things?”...But at the camp, she was surrounded by quirkiness...and since we’ve come back, we’ve seen a couple kids in wheelchairs, you know...there was another little boy who was walking by and he had no hair, it was at the zoo, she walked right up to him and said, “Do you have cancer in your head too?” And he turned around, and he was like five or six, and he was, “NO! It’s in here!” (points to torso) and she goes, “that’s an ow-y...your hair will come back, look at him,” and she’s pointing to my son [the child with cancer]. She had this frank little conversation with this little boy...and then they just kinda split. But she got it. I don’t know if cancer camp was the one thing that kinda kicked her, and she saw all these different kids that were different and stuff, but she was nice about it, she was friendly and she actually hugged this little boy before we walked away...But it was nice, and to me, I was like, ok, and I attribute that to camp because there was kids with no hair,
some hair, whatever, didn’t matter. They don’t feel good so just treat them nicely, like be a little more gentle with them. So both of them, you know, she [Molly] got kind of an empathy and understood a little more than I think she did with her limited exposure, cause she wasn’t allowed at the hospital, she wasn’t allowed in the room, wasn’t allowed to see these sibling. Everyone lived in their bubbles.

What it means to be other than the self is much written about in philosophical literature. Levinas (1969/1980) pointed out that Western philosophical tradition has historically favored the self at the expense of the other. Postmodern thought, in response, insists on the absolute otherness of the other – every other is wholly other (Treanor, 2006). The middle ground, argued for by contemporary theorists, is every other is truly other, but no other is wholly other (Treanor, 2006). This is exactly what I think is happening to these children at camp. They recognize themselves in the Other, and with that recognition comes an ethic, a responsibility they cannot ignore, to open of themselves, put themselves in a place of vulnerability, and heed the call of the Other.

**Camp is Not for Everyone**

Not all families in the community of childhood cancer like, and go, to camp.

Several parents offered their thoughts as to why:

> There was a family there today, they were picking up their boys, and ah, they had actually signed up for family camp and didn’t go cause they just didn’t think they could handle it emotionally, and I totally understood that.

> ...her daughter had just died and she says no, I, I hate cancer, I hate that it took my daughter away and I don’t want to have anything to do with it. So it’s not as if
camp has anything to do with it, they don’t want…they were so mad at the fact that [she] had cancer, and they lost their child, that they pushed everything back…it’s easy to do that, it really is so easy.

Sometimes families reject the community into which they were thrust, and shun being included in its sensus communis. Estefan and Roughley (in press) suggested that we can live in communities of conflict, where opposing interests and perspectives bring us awkwardly together, creating contested ground, but community none-the-less. While families may be a part of a community in the way that their child shares a diagnosis of childhood cancer, that does not mean that they are there willingly, or to participate. It reminds us that there is more to the sensus communis than a shared diagnosis. Estefan, McAllister, and Rowe (2004) cautioned that the “common” sense that arises from experience can become “dominant” sense, and those who do not (or cannot) share in this common sense may be marginalized or ignored. I do not know if this is what happens to the families who choose not to participate in cancer camp. My experience in the interviews was that parents, like in the above quotes, understood, and were even sympathetic, toward others that chose not to come to camp. It is worth the note of caution, however, to recognize that there are always those who will feel they do not belong to, or are not a part of, cancer camp.

Concluding Thoughts

He had tried to understand why people who had survived war together found it much easier to deal with their trauma than those who had faced the same kind of outrage alone. He wanted to discover why individuals in a group who had been tortured or raped, or had seen their families killed, were able to heal their wounds
more easily than those who had suffered alone. What is it about community that heals us? Is it reflection, channeling, the very normalization of trauma? Or is it, in fact, solidarity? (Kepler, 2011, p. 260)

It is hard to ignore that within the word “community,” the word “unity” is right there. I expected to find, when looking up the definition of community, something saying “common unity,” but to my surprise, I did not. Unity and solidarity are synonyms of each other, and Kepler’s (2011) quote, though from a book a fiction, offers insight into what I believe to be at the heart of the sensus communis of this community of families; solidarity. “Solidarity” comes from the French solidarité, meaning “mutual responsibility” (Etymonline, 2012). These families feel a mutual responsibility for one another. Their adversity bonds them in solidarity to care for one another and for each other’s children, as well as their own. They realize they cannot do this alone, and the unity of this community – the mutual responsibility or solidarity they enter into once they become a part of it, makes them realize they do not have to do this alone. How camp figures in this, I believe, is by acting as the catalyst for this to happen. Parents described “feeling alone” and “living in a bubble” until they came to camp, and became aware of the community to which they now belonged. The act of coming together at camp helps families to understand how they fit into the bigger picture. It is this mutual responsibility that contributes to what Kepler was referring to in the healing power of community.

“Knowing that this kind of a community is there is actually a relief...they care and everybody out there really, really cares. And they feel it – you feel like you’re part of the big family.” (Parent)

There are unique elements that contribute to the sensus communis in these
families, and no doubt other hermeneutic researchers would interpret it differently or offer alternate perspectives. Hermeneutics is, after all, the answer to a question that could have been answered differently (Gadamer, 1960/1989). However, I believe safety and control, and recognition of the Other to be some of the most unique, representative elements of what contributes to the “common” sense of this community.
Chapter Nine: “It’s not just camp” – Returning to the Title

I recognized Jeremy immediately, although he was much older now. He used to be a patient in the cancer program when he was little, and he now wore the scars of his treatment in the form of a noticeable limp, contracted hand, and hearing impairment. It had been at least ten years since I last saw him, but there was something about his demeanor that had etched itself in my memory. Now, he was the counselor assigned to show me around camp on the first day, and I was looking forward not only to seeing the camp, but also to reconnecting with him. As he began the tour, I asked him questions about what his life has been like over the past while. He told me about being estranged from his family – they think he is too attached to his “cancer life” he said – and described how he felt he had “grown up,” at camp. Now responsible for the audiovisual elements of camp, Jeremy lives off his camp earnings and disability income – a humble existence. Around the time when I was wondering just how big camp was (we were now an hour and a half into our tour), I noticed a tattoo on his arm, partially hidden by his shirt, and asked him what it said. He grinned, and lifted up his sleeve to show me: ““All you did was save my life.” It’s dedicated to kids with cancer, to the camp, cause who knows what I’d be without it? All you did was save my life.” Jeremy described feeling like the camp, and the cancer families, were his family now, and how he could not imagine doing anything else with his life. His “cancer life,” as his family referred to it, was all he had.

I have pondered extensively over Jeremy’s tattoo, “all you did was save my life,” and the profundity of it. It is a figurative phrase, I assured myself, however later felt challenged on that certainty, because how do I know that camp did not, in fact, literally save his life? He knows more than I, about the meaning behind those words. However,
the more I considered Jeremy’s tattoo, the more I felt it also spoke to the title of this dissertation: *It’s not just camp.* There is a certain inarticulateness to camp; how to translate the depth of what can be experienced there, in a way that allows others to understand, is very complex. Convincing others of the merits of this camp, how important it is to children and families undergoing childhood cancer, is something that is accomplished by more than research studies and dissertations – it is achieved by knowing that someone like Jeremy, a counselor and survivor of childhood cancer, credits cancer camp with saving his life.

Moules (2009) reminded us that the value of the findings in qualitative work lies in their utility, and in how they influence the work that we do. With this in mind, the following section pertains to the utility of the findings of my research – in other words, what difference do they make?

**Returning to the Question**

The original research question was, “How might we understand the meaning of cancer camps for children and their families?” Looking back on this question, now that I am on the other side of the research, my immediate, slightly flippant answer is, “we can’t.” What I mean is, we can never fully understand the meaning of these camps for these families because it means something different for everyone. No matter how extensive the research, or how diligent the researcher, there will always be families that do not find their experiences reflected, or do not feel represented, in the finished product. Hermeneutics however, has not asked me to conclude anything decisively, rather, it has asked me to offer a version of something that might be true. Hermeneutics does not claim to offer *the* truth, but must be true of something (Gadamer, 1960/1989).
I do not wish to return only to the original research question, rather I wish to return to it in the context of the title of this dissertation: *It’s not just camp*. The research question and title are connected, because by understanding *why* it is not “just camp,” we start to understand the meaning of cancer camp for the child and family. Over the past five chapters, I have offered my interpretations in hopes of furthering understanding around this topic, of understanding why camp is not just camp, however I do not believe that, in hermeneutics, the question is ever fully answered. Life is messy, as Jardine (2006) noted, and somehow we lose something that is important when we try to flatten it out and make it orderly. Therefore, as I return to the interpretations in the spirit of understanding their utility and applicability, it is with the recognition that they will always remain complex and “un-flattened,” and they may not ring true for all who read them. It is my hope though, that for most families, they are true of something.

**Returning to Play: The Launching Point of Understanding**

So important is the concept of play\(^5\) that I claimed it to be the “the fundamental concept from which all further interpretations arise” (p. 53). In order to truly understand any of the interpretations I offered, one must consider them within the context of what is “at play.” The “at play-ness” of a concept allows us to consider the history, traditions, and prejudices that accompany these concepts, and allows the reader to understand what is happening. For example, I offered the idea, in Chapter 5, *The Island of Misfit Toys*, that the complete and unconditional acceptance of children at camp allows them to understand that they are differently suited to their environment. This idea, on its own, is limited in how it contributes to new understandings. In order to fully appreciate this idea

\(^5\) Play, in the sense of what is “at play” in children and families at cancer camp.
of “differently suited,” one must first understand all that is at play in this concept – the history behind it (e.g., why there exists a “misfit” in the first place), the scholarship around the importance of acceptance, and what happens to the children when they realize they “fit” at camp. There is much “at play” within any given concept in an interpretive setting – nothing exists independently, and everything is connected. In order to recognize what is at play, often a troubling or disruptiveness of the familiar is required. By troubling a concept, hermeneutics takes the familiar and assumed, then exoticizes, complicates, and disrupts it, and returns it back to the familiar so it is understood differently (Gadamer, 1960/1989; Moules, 2002; White, 1993). Hermeneutics helps us understand what is at play.

I believe that by being attuned to the concept of what is at play, the reader is able to more fully appreciate the concepts offered in the subsequent chapters, and consider the history and traditions that have brought the concept from where it was, to where it is currently. It can remind us that there is always an “at play” in virtually any situation we encounter, especially as nurses, as nursing is an interpretive practice. Be it an encounter with a newly diagnosed family, or one that is recently bereaved, it is important to remember, and ask ourselves, to be aware of all that is at play in any given situation in order to truly understand the complexity, and to let the complexity breathe.

**Returning to Misfit: Finding Fit**

Cancer does not fit well in the regular world. Simply by virtue of receiving that diagnosis, the children and their family members are immediately placed in a situation where they no longer fit. We cannot underestimate the importance of what it means to find fit with something, somewhere. For many children with cancer, the first time they
feel completely accepted is when they come to camp. Counselors and parents reported the changes in the children – what I believe to be the “side effects” of finding fit and acceptance – as increased confidence, improved physical ability, compassion toward others, and improved social skills. In many ways and for many children, camp is an oasis, a place that provides “refuge, relief, or a pleasant contrast” (Merriam-Webster, 2012), from the severity of their disease.

They have different activities there [at camp] that help you come out of your inner shell, you know, like the high ropes and the wall climbing...stuff that they had done before when they were younger that they would get to do, and activities that would build them together, like unity building activities to help you strengthen one another, and rely on one another, so that you realize you’re not in this alone, and that you can laugh and have fun and play and just be yourself, and yes, cancer’s happened to your family, but you don’t need to worry about that, cause life goes on. (Parent)

For parents, camp offers the opportunity to connect with, support, and be supported by, other parents of children with cancer, and for them, their refuge – their acceptance – comes by way of “me too” moments – moments that allow them to feel they are not alone. By recognizing their experiences in others, camp provides opportunities for parents to come to revisit, and re-know, their experiences with childhood cancer, and allows them the opportunity to process traumatic events and emotions differently.

I demonstrated how, when mis is separated from fit, the word misfit can be understood differently, as something, or someone, that is “differently suited” to the environment, versus the traditional definition of “a person who is poorly adapted to a
situation or environment” (Merriam-Webster, 2012). It is a reminder to challenge preconceived ideas and dominant discourses, and to remember that there is always another way to understand something, or someone.

**Returning to Grief: Living With, Versus Getting Over**

When we consider that grief can be understood as an experience that changes over time, but is never completed (Silverman & Klass, 1996), yet society treats grief as an experience one does, indeed, “get over,” it is not surprising to understand how families experiencing grief might find tension in this dichotomy. At camp, families are not expected to get over their grief; in fact, I have offered that they are given space in which to understand their grief differently. One parent shared these thoughts:

> [Camp has] really helped the kids understand that cancer was a part of our life, and we don’t want to just close that chapter, we want to embrace it, understand that it happened to us... camp is like our therapy.

> I think it helped [my son] because it was his brother that he lost. He was very upset about it. He had a very hard time, but camp was somewhere he could go, and he could talk freely about it, he could meet other kids who had a brother or a sister that had cancer, and he didn’t have to hide from anybody, he didn’t have to, you know, hide his fears or anything – he could just be himself. If he was upset he was upset, if he was grumpy he was grumpy, and no one was going to judge him for that.

It is also important to acknowledge the sanctity of the rituals at camp. From magical moments to luminaries, these rituals recognize the extent to which the mental
and physical are intertwined (Wright, 2008), help families remake their world (Bell, 1992), and come to new ways of knowing their grief. To an outsider, camp might appear fun and haphazard, and while it is indeed fun, everything there is done with intention. The rituals of camp offer comfort to children with cancer and their families experiencing grief, and allow for the weight of their grief to be shared, and understood differently.

Returning to Storytelling: Understanding Differently

There are endless stories told at camp, and of camp. In telling stories, children make sense of their lives (Widdershoven, 1993), and are often able to re-process traumatic and confusing events in a way that makes sense to them (Abma, 2005; Bosticco & Thompson, 2005). Camp offers the time, space, and opportunity for children to tell their stories. It also gives them the “material” for their continued stories once they return home from camp, and re-enter the “real” world. This research can serve as a reminder to those of us who work with children, that the importance, the “point,” of children’s stories lie in their landscapes (Stevens, 1981), and in order to truly understand, we must consider these landscapes. Doing this implies an oblique approach – what I have called “peripheral listening,” because one loses the point by listening straight on.

The stories of parents are filled with gratitude, and camp provides parents the opportunity to feel gratitude and express gratefulness. It is by the telling and retelling of their stories that parents and children can come to understand the meaning of childhood cancer differently.

Returning to Community: Sensus Communis, “Common” Sense

By bringing families to the same physical location, the community of camp instills connection among these families, creating a sensus communis. It is this sensus
communis, I surmise, that contributes most to the belonging, understanding, and acceptance so often described by parents in this research. There can be a healing power in a community, where those who have lived, or are living, through something traumatic, are able to find greater healing than if they were not a part of the community. It is at camp where, often for the first time, families realize they are not alone in the experience of childhood cancer, and often where they can begin to live again. As one parent described:

*The little bubble that the family lives in is that much bigger [at camp], because you’re taking this little bubble that is our home, or his room, or whatever, and you’re expanding it to this huge acreage where they can run and do things, and it’s just as safe as being in this little bubble here.*

Parents described, as a result of camp, increased compassion, empathy, and understanding, particularly in the siblings of children with cancer, toward children who were visibly, or behaviorally, different from themselves. The community of camp exposes children to many others who are different from themselves (e.g., missing limbs, scars, etc.). They are repeatedly confronted with “otherness,” and this exposure has them recognize themselves in the Other, understanding they are more similar, than different.

**So What?**

You are encouraged, upon occasion, in doctoral studies to have an “elevator pitch” of your research – one or two sentences that capture the essence of your study, that you could tell to a stranger in the span of an elevator ride. This was mine: “I’m looking at understanding the meaning of cancer camps for kids with cancer and their families. In other words, we know camp is (generally) a “good” thing, but why? Of equal
importance, why does it matter?” If there is one takeaway from this research I wish to communicate it is this: Children’s cancer camps need to be considered a necessity, versus a luxury, and should even be thought of as a psychosocial intervention for some children and families. The words “psychosocial intervention” might carry a negative connotation, as if without it the family would be destined for disastrous outcomes. To intervene means to occur, or lie, between two things (Merriam-Webster, 2012), therefore I am suggesting intervention in the sense of “lying between” merely existing and fully living, between suffering and enjoyment, and between feeling isolated and feeling a part of something. I am also not suggesting that families and children should be forced to attend camp, but rather that camp is considered important enough by the healthcare staff that it is promoted, discussed year round, and that every effort is made to send these children and families.

In order for cancer camp to be considered a necessity or a psychosocial intervention, it is important to understand where the current barriers lie. One barrier is in the way camp is funded. Cancer camp is a philanthropic entity, funded by public donations coming from individuals or corporations. Sometimes called “soft money,” this type of funding is not secure; there is no guarantee it will be there next year, and predicting donations is a precarious exercise, largely based on the financial health of the local community. Concurrently, the Government of Alberta (2010) has recognized the increasing pressure on the health system to meet the changing health needs of the population, and has deemed “innovative health service delivery” as a strategic priority for health, prompting Alberta Health Service’s (2009) mission statement to include a patient-focused, quality health system that is accessible and sustainable for all Albertans.
camp, it could be argued, is an “innovative health service delivery” model – it delivers
psychosocial care to these families in a powerful, efficient, and effective way, that is
external to the regular healthcare system. If cancer camps were to be considered a
necessary part of children’s cancer care, and were to become funded (partially or entirely)
by our healthcare system, there would no longer be the continual threat of sustainability
of these camps due to a decrease in donations (particularly during times of recessions),
and it would fulfill the mandate of the government to provide innovative, cost-effective,
healthcare. Similarly, if organizations like Kids Cancer Care did not need to rely on
public donations to fund the children’s cancer camps each year, they could broaden the
scope of funding opportunities, using money to support other programs related to
improving the quality of care of children and families of childhood cancer (for example,
more pediatric oncology research).

An additional barrier lies with patient care managers and hospital administrators;
these are the people who must be encouraged to facilitate staff (particularly nurses)
having time off to attend camps as “camp nurses.” Having trained pediatric oncology
nurses attend camp is extremely important. Without them, cancer camp could not exist,
as children often require treatment, and occasionally there are medical emergencies that
require staff trained to recognize and handle them. It is difficult for nurses to be granted
time off for this purpose from their positions at the hospital, given the “separated-ness”
cancer camp has from hospital programs. Every year, staffing these camps is a challenge
for organizations like Kids Cancer Care, and having hospital administrators “buy in” to
the importance of these camps could help facilitate this process. It is my hope that this
research might serve to persuade these decision makers, allowing camp to be considered
part of the regular treatment for children with cancer, and ensuring easier access to trained professionals.

**Concluding Thoughts**

*I was talking to one of our counselors, and she’s also a survivor...she had cancer when she was three, I think, and she remembers the hospital as a place that hurt her, like where she got needles and stuff, so she said the thing that she likes to remember – like the happy place in all of that darkness – was camp. (Counselor)*

Camp fulfills different needs for different families, but one commonality I found was that a tremendous amount of healing occurs at camp. Depending on where the child and family are in the cancer journey, this healing is different for everyone. Like Sharon, it may come by way of being invited to tell a story of incredible pain, and allowing the enormity of that grief to escape, and be shared, by others. For Linda, it comes by knowing her family is safe, and at peace, at camp. For the McMahon family, their son now six years deceased, their healing seems to happen by way of giving back to this community, and helping others. There are as many kinds of healing as there are families that attend camp, and while I could never know them all, their stories all speak to healing themselves, and others, and finding “the happy place in all of that darkness.”
Chapter Ten: Determining Value – The Metrics Upon Which Camp is Measured

I had a talk with my uncle who’s actually on the Board of Directors [of Kids Cancer Care], and he and [another board member] were talking, and he was telling me that they’re trying to figure out ways they could explain it, so why should kids be coming to camp, why is it important, and it’s all about numbers, and you know, how is this helping them in their cancer journey...in their diagnosis. And I think looking at it strictly in just the number basis is the complete wrong direction to go. Because, when the kids are here, we’re not bringing the kids here so that, you know, they’ll get healthy quicker, or so that, you know, it’s going to make some difference in, in the medical treatment that they go through, cause it’s not. Camp is all about giving these kids a chance to no longer be just “that kid” with cancer. It gives them a chance to be that kid that they’re missing out on as they grow up, because of this cancer. They don’t get a chance to experience all of the stuff that, you know, some of the other kids that maybe haven’t lost a limb or didn’t go through chemo and had to sit in a hospital for 6 months...these kids have to grow up and they mature really fast, and it’s because they’re forced into a position where, you know, if they don’t mature right away, it makes it way harder to get through what they’re going through. And so, coming out to camp and getting to experience something that is regular to childhood, that actually puts some normalcy into their life that they’re missing, makes a huge amount of difference just, you know, to mental stability and to happiness. And really – that’s the whole point of camp, is just having some happiness somewhere, that in, in...um, all this darkness there’s some daylight.
And ah, I think that’s a point that’s overlooked a lot when it comes to thinking about why am I donating here, why is that important. And I think in this day and age when everything is rush, rush, rush, dollars and dimes, the idea of mental happiness is just not there anymore. And ah, I think it’s far more important than I think a lot of people actually think. (Counselor)

I must be disclosing here, and share three particular areas of my background in order to frame the rest of this section. I used to be the Patient Care Manager of the Pediatric Hematology, Oncology, and Blood and Marrow Transplant Program at the Alberta Children’s Hospital. I managed a staff of 140, had an operating budget of 10 million per year, and had responsibilities at the local, provincial, national, and international level. Every month, I would receive 15 to 20 reports on my budget, ranging from how much money was spent on medical supplies to salaries and sick time, and I was responsible for ensuring I was meeting my financial targets. It was not uncommon to be given a mandate stating I needed to trim a certain percentage of my budget in any given reporting period, and it was left to my discretion to figure out how to do that. Alberta Health Services (AHS), my employer, made it very clear that it was always about the money. I am perhaps painting a grim picture in some respects but, in truth, I cannot fault them for this. They are responsible for ensuring the sustainability of healthcare in our province, and the vast majority of their decisions need to be centered on fiscal responsibility. As a consumer of healthcare, I want them to do whatever they need to do to ensure I can access medical care whenever I need to. As an employee of the healthcare system, it made it hard to consider anything other than my bottom line and financial targets. Additionally, when I first started my doctoral studies, I met privately with the
former Chief Nursing Officer to discuss what kinds of roles existed for PhD prepared nurses within AHS. In no uncertain terms, I left knowing that the only research AHS was interested in was that which could provide cost savings. They only valued quantitative research.

The second area of my background I wish to share is when I sat on the Board of Directors for Kids Cancer Care, there were many discussions around how to measure the return on investment (ROI)\(^6\) of cancer camp. It was a practical discussion, in one sense, as donors were starting to require more “proof” of the benefit of these camps, rather than simply accepting, at face value, that camps were beneficial. Proof, for donors, comes by way of numbers and statistics – something to show them how far their dollar goes – and little else seems to be considered worthy evidence. Camp though, is difficult to measure, and as one board member pointed out, “Are we sure we even want to know that answer? Furthermore, what if all we find out is that camps do nothing except diminish their suffering for a week?” He meant that measuring constructs related to camp (e.g., self-confidence) might not yield any statistically significant results, or worse, might indicate undesirable (negative) results. Not surprisingly, it has proven extremely challenging to determine the ROI of cancer camps.

The last thing I wish to share is the tension I have felt with respect to living in the world I have just described, yet studying in the tradition of philosophical hermeneutics. I struggled significantly early on, at one point even discussing with my supervisor that I felt I was more suited to quantitative research, and seriously considered switching tracts.

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\(^6\) A performance measure used to evaluate the efficiency of an investment or to compare the efficiency of a number of different investments. To calculate ROI, the benefit (return) of an investment is divided by the cost of the investment; the result is expressed as a percentage or a ratio (Investopedia, 2012).
Obviously, that did not happen (for many reasons) and as I sit here today, I am very thankful it did not. I cannot, however, say that I have reconciled the tension I felt around the *perception* of the value of hermeneutic research in the world where bottom lines, money, and data reign supreme. Many people, I offer, do not “get it,” and I have had many instances where I have realized the value of the hermeneutic research is being lost on them because they are so focused on, “What do you mean there is no method? Why is the sample size so small? You did not use random sampling?” They are always caught up in the fact that there are no numbers, statistics, or data (in the quantitative sense), and I have felt frustrated at their lack of understanding around the value of hermeneutic research. Yet, when I remember the history and traditions from where I have come, I understand their ignorance.

I straddle two worlds and suspect I always will, so with this in mind, I am compelled to find a solution to live comfortably in both; in the hermeneutic world, recognizing everything is interpreted, and the world that is connected to bottom lines and money. I propose that they do not need to be as far apart as they currently are, and a bridge connecting the two could allow for more understanding and appreciation. I believe that by turning the conversation from cost to social value, such a bridge can be built.

**Social Return on Investment**

A social return on investment (SROI) is a relatively new methodology that uses a principles-based approach that values change that would not otherwise be valued (SROI Network, 2012). It assigns monetary value, by way of financial proxies, to traditionally non-valued, overlooked, or misunderstood things such as the environment, quality of life,
and self-confidence (SROI Canada, 2012). An SROI offers a common language between those who are familiar with the value of projects, like an organization (e.g., AHS), to investors with less information or understanding. It shifts the conversation from cost to value, by measuring the impacts that really matter (SROI Network, 2012).

SROI is a framework based on social generally accepted accounting principles that can be used to help manage and understand the social, economic, and environmental outcomes and help to account for the wider impact that may be known to exist, but is difficult to articulate. Value is created in many different ways, and SROI is an approach to understanding and accounting for social value, and being able to communicate clearly and credibly, where and how value is created.

SROI is based on seven principles:

- Involve stakeholders: Understand the way in which the organization creates change through a dialogue with stakeholders.
- Understand what changes: Acknowledge and articulate all the values, objectives and stakeholders of the organization before agreeing which aspects of the organization are to be included in the scope. Determine what must be included in the account in order that stakeholders can make reasonable decisions.
- Value the things that matter: Use financial proxies for indicators in order to include the values of those excluded from markets in the same terms as used in markets.
- Only include what is material: Articulate clearly how activities create change and evaluate this through the evidence gathered.
- Do not over claim: Make comparisons of performance and impact using
appropriate benchmarks, targets and external standards.

- Be transparent: Demonstrate the basis on which the findings may be considered accurate and honest, showing that they will be reported to, and discussed with, stakeholders.

- Verify the result: Ensure appropriate independent verification of the account.

(SROI Network, 2012)

By way of financial proxies (along with many other considerations), an SROI is determined, expressed as a ratio (e.g., 1:SROI). This ratio then allows the organization the ability to say “By investing $1 in this program, X amount of dollars are created in social value over a 1 year/5 year period.” It is a story, not just a number, and the story demonstrates how to understand the value created. Since this is social impact that is being valued, it is never just about the money; there is always context associated with it.

I have taken several pages to explain parts of my background that have led me to where I am today not to be self indulgent, but rather to offer a tracing, of sorts, for how I have come to see the value and necessity of using something like SROI as an accompaniment to hermeneutic research, when the value of something is warranted. Cancer camp, for instance, has a value to it. My research, it could be said, has pointed to some of that value – play, storytelling, finding fit, grief – things that we know inherently and intuitively to have value, yet are difficult to use in a context where numbers and cost prevail. These interpretations I have presented as a result of my research could be thought of as the context that accompanies an SROI, and the first step toward identifying what kind of social impact cancer camp has on the child and family with cancer. I believe what is really desired by the Board of Directors when they express the need to
“figure out the ROI of camp,” is understanding what kind of value camp has, and how to best communicate it to the public in a way that is understood. I suggest that in order to truly understand what camp is worth – how to put numbers behind it that appeal to donors and other funding agencies – it is more the social value to which we are referring.

I guess for me, I ah, I’ll never forget the first time as a camper getting off the Edmonton bus and the welcoming, the excitement the counselors had – right there I was hooked immediately. All these years I thought I was alone in this whole cancer thing. I didn’t know anybody else who had it, and yeah, getting off that bus knowing there were other kids like me…and yeah, I knew it’s what I wanted to do for the rest of my life. (Counselor)

Hermeneutics yields powerful, meaningful findings, and it is important that this kind of research not fall on deaf ears. I feel obligated to find a way to bridge the gap between the powerfully compelling world of hermeneutics, and the other world, where money rules. I live in both, and it is a cautious dance between the two at times, but I feel the onus is on me to find a way in which to bridge this gap. SROI, I believe, is one of the ways in which this can be done.

**Trustworthiness and Validity**

Qualitative research is evaluated by different criteria of rigor and validity than quantitative research (Koch, 1994). Rigor, in a hermeneutic study, is demonstrated by the believability or trustworthiness of the study (Koch, 1996). Credibility, transferability, and dependability are the constructs upon which trustworthiness (rigor) is established (Guba & Lincoln, 1989).
Credibility within trustworthiness. To demonstrate credibility, a study must be believable; it must be true of something (Carnevale, 2002). Guba and Lincoln (1989) offered that a study is credible when it presents faithful descriptions and readers can recognize it. While some qualitative methods propose a triangulation of data sources or external referencing to establish credibility (Polit & Beck, 1978/2008), this approach is not supported in hermeneutics. Allen (1995) suggested “(t)he strategy of returning to the subjects for validation is often based in a mirror epistemology in which the goal is to copy or reproduce the original meaning of the subjects’ responses. This is questioned in hermeneutics” (p. 179). Instead, researchers engaged in hermeneutic inquiry may choose to have their interpretations read by others as a way of establishing credibility for their study. Moules (2002) described this as an action “in recognition that hermeneutics honors that all things can be answered differently” (p. 33) and having interpretations read by others provides the opportunity to further expand upon them. Throughout the course of writing my interpretations, my supervisor, Dr. Nancy Moules, read each interpretation and offered her feedback. In addition, my supervisory committee also read each chapter, ensuring that each interpretation was fully developed and considered in full. An example of this is in Chapter 8, Community as Sensus Communis, Dr. Andrew Estefan, a member of my supervisory committee, offered this comment: “We also live in communities of conflict, where our interests are oppositional and it is the opposition that brings us awkwardly together, creating contested ground, but community none-the-less.” I had not considered this within the context of sensus communis, and thus, incorporated it into the discussion within the context of why some families do not attend camp. Having others
read the study and offer feedback and insight that might not have been otherwise considered, the credibility of this hermeneutic research was enhanced.

**Transferability within trustworthiness.** Lincoln and Guba (1985) proposed the term transferability for qualitative research (versus generalizability) as it describes the degree of similarity between two contexts. The degree of transferability depends on the similarity between contexts, therefore the more accurately the conditions and contexts under which the research was conducted is described, the more likely the reader is to find similarity to another situation. In other words, the interpretations “fit into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences” (Sandelowski, 1986, p. 27). Koch (1996) suggested incorporating sections of journal data or field notes into studies to improve the transferability of the interpretations as this helps clarify the conditions under which interpretations are arrived at so that a judgment of transferability may be made by the reader.

My use of vignettes, quotes, descriptions, and stories from camp was to give the reader a clear understanding and sense of what it might have been like to be there. It was my hope to convey a deep understanding of the context, look, and “feel” of camp, and to write in such a way as to, in some instances, give the reader a sense of “I know what that is like.” For instance, my opening paragraph in Chapter 4, *In Play, at Play*, I wrote the description of my conversation with Molly in a way that I felt best captured what was happening. It could perhaps be criticized in an academic forum for being a “non-academic” style of writing, however in order to really understand – to “get it” – I believe one must take liberties with writing style in order to convey a mood, sentiment, or
moment, in such a way as to have the reader understand, and thus, be able to find similarity to another situation.

**Dependability within trustworthiness.** The degree to which a study can be audited represents the dependability of a study (Koch, 1994). Sandelowski (1986) stated “(a study) is auditable when another researcher can clearly follow the decision trail used by the investigator in the study” (p. 33). Koch (1994) suggested a decision trail is a way in which to facilitate this process. A decision trail combines theoretical, philosophical, and methodological decisions and has the potential to clarify the research process and establish trustworthiness of the study. It demonstrates the process by which interpretations have been made (Koch, 1994).

Interprete memos were done for each interview that I conducted, and are demonstrative of how I came to the interpretations that I did. Each interpretive memo contains quotes and beginning interpretations, or thoughts, related to what struck me about the interview. I offer a small (unedited) excerpt from my interpretive memo with the McMahon family, as an example:

**Luminaries**

- “they put a candle in it but first you have to decorate it and write a memory of your somebody special that has cancer or passed away from cancer and then you make the luminary around it, you glue it on top and then you put it in the water and you say a prayer or make a wish and you put it off into the pond, and it’s dusk at that point and it’s all lit…it’s really beautiful.

- Such a great visual…use this somehow? Light, ceremony, symbols (Gadamer), ritual (Gadamer)
Luminaries showed up in Chapter 6, *Grief: “The Bleached Bones of a Story”* (Roy, 2008, p. 33), within the context of camp as ritual. One can see, by this excerpt, that the idea was formed by the quote associated with it, but much further developed in the interpretation. It is by keeping detailed accounts by way of interpretive memos (decision trails) that the dependability of a hermeneutic study can be enhanced, as one would be able to follow how an interpretation was developed.

**Validity.** Validity is defined in terms of being well grounded or justifiable: being at once relevant and meaningful (Merriam-Webster, 2012). It implies being supported by objective truth or generally accepted authority, and in the traditional scientific sense, validity is to make something repeatable. In qualitative work however, repeatability does not equal validity. Moules (2002) asserted that truth or validity in the hermeneutic sense does not comply with the scientific requirement of repeatability; rather it lies in its capacity to “last, linger, and even change” (p. 23). Validity in hermeneutic research is aletheia at its best – it enlivens, opens, and reminds us of what was once dead, closed, and forgotten. It challenges that which has been taken for granted and assumed, and calls for the reader to re-member, re-call, and re-vive. Moules stated:

Validity in interpretive inquiry, according to Lather (1993), is a form of recovery and legitimization which incites discourse. Validity lies in the attempts to resist closed truths of the past encased in the shape of rigid, tight arguments, to recover possibilities, and to free the present for discussion, new thoughts, and practices. First and foremost, validity is an experience of application; it does not arise out of the past but from the future, becoming something only in the way it is lived out. (p. 35)
In addition to the above, validity is demonstrated in hermeneutic research when the study is true to the philosophical paradigm with which it aligns itself, when the interpretations are justifiable and are true of something, and when the interpretations are relevant and meaningful, adding to the body of knowledge on the intended topic. “Truth” in interpretation is a meaningful account that corresponds to experience (Davey, 2006). There may not be an absolute answer but there may be better answers that help bring forth understanding.

Additionally, as indicated earlier, interpretations were shared with my supervisor, Dr. Nancy Moules, and my supervisory committee. Dr. Moules is a well-known hermeneutic researcher with a distinguished record of research that will serve to increase the credibility, trustworthiness, and integrity of the work that is being presented.

Another factor that contributes to the validity of hermeneutic work is the ability of the author to express him/herself in such a way as to have the research “last, linger, and even change” (Moules, 2002, p. 23). In order for research to have such an effect, the researcher needs to be able to write in such a way as to draw the readers in, grab their attention, and present the interpretations so they are attainable, understandable, recognizable, and true of something. In other words, researchers not only need to be true to the tradition of hermeneutics, they need to be good writers.

**In summary.** A story must be judged according to whether it makes sense. And “making sense” must be here understood in its most direct meaning: to make sense is to enliven the senses. A story that makes sense is one that stirs the senses from their slumber, one that opens the eyes and the ears to their real surroundings, tuning the tongue to the actual tastes in the air and sending chills of recognition
along the surface of the skin. To make sense is to release the body from the
constraints imposed by outworn ways of speaking, and hence to renew and
rejuvenate one's felt awareness of the world. It is to make the senses wake up to
where they are. (Abram, 1996. p. 265)

It is my hope that this research is valid in the sense that it is telling of something,
and that truth lies in the possibility that the interpretations have opened up the topic of
and always becoming, and the interpretations I have offered are not because I believe
them to be true but because I believe them to be the best (Madison, 1988). The work is
deeded valid when the reader acknowledges, “ah, yes, this is right,” and there is
resonance with the topic (Gadamer, 1960/1989).

**Limitations, Strengths, and Future Research**

Davey (2006) argued that the limitations of hermeneutics are also its strengths,
and while this may be true, I have chosen not to frame this discussion in such a fashion.
Sometimes when researchers do this – present the limitations of their study as strengths –
it resembles a “linguistic trickery,” of sorts – and I am left, as the reader, not clear on the
limitations in their study. Every study has limitations, as it is impossible to completely
predict, account for, or address all methodological aberrances, and this study is no
different. However, I believe this study also has strengths, as most do, and I wish to stray
from tradition slightly, and address what I see to be the particular strengths as well.

**Limitations.** The biggest limitation of this study is that the interpretations may
not be understood by, taken up, or resonate with those who read them. This is a
limitation not just of my research, but also with all interpretive work. Hermeneutics is
always the answer to a question that could have been answered differently (Gadamer, 1960/1989), and as such, I and other hermeneutic researchers can never escape the fact that our research may not be as impactful as we would have liked.

Limitations lie not only in the research but also, at times, in the researcher, and I believe in order to be comprehensive in my discussion, I also need to acknowledge the limitations that lie within myself. I am not as “practiced” at hermeneutics as others who research in this tradition. I do not yet know hermeneutics to the depth some might say is required in order to be true to the philosophy. Another hermeneutic researcher, for example, might have been able to take the exact same interview transcriptions and offer more robust and resonating interpretations, thus furthering the understanding more than I was able to do. Additionally, I tend to be parsimonious with words, when hermeneutics often calls for the opposite in order for understanding to occur. To these limitations, I can offer that it is conceivable that, as I become more practiced in the tradition of hermeneutics, I will be able to offer different, perhaps more robust interpretations that will serve to further understanding. My “parsimonious-ness” with words, however, is unlikely to change, and may always be a limitation of mine.

This study was undertaken within a doctoral program in the Faculty of Nursing at the University of Calgary and some might wonder at the fact that the interpretations offered are not nursing specific – in fact, the word “nurse” rarely appears in this dissertation. It is true – this is not a nursing-specific dissertation. However, it is not specific to any discipline – it is specific to children with cancer and their families and how we might understand what kind of meaning children’s cancer camps have for them. The understandings that have come from this research can be utilized by anyone, and just
because I am a nurse does not imply that this is only nursing knowledge. In fact, in the original design of this study, I was intending to interview the camp nurses, not the counselors. It became quickly apparent to me, however, that the counselors were the ones who would be able to give me the kind of information I was seeking by virtue of the amount of time and types of interactions they had with the children and families. I needed to stay true to the research question (versus my discipline) and seek out participants that could best inform the topic.

**Strengths.** Gadamer (1960/1989) said that “always, already” is the starting point for hermeneutics and that, in hermeneutics, we are stepping into something that already is. That “something that already is,” is part of our lifeworld, and Husserl (cited in Dowling, 2007) reminded us that we already know something about it – we do not generally start from the beginning. I already knew something about children with cancer and their families. I had worked with them in many capacities for 15 years, and my prejudices (in the hermeneutic sense of pre-understandings) were well formed. I believe this to be the greatest strength of this research, because of the fact that, in interpretive work, not only is there is always a relationship between the researcher and the researched, but there is also a relationship to the particular (Smith, 1991). Interpretive work, said Smith (1991), makes you more susceptible to the particular, and because of my background and history that have formed my prejudices in this respect, I was intensely susceptible to the particular, in this research. I believe my prejudices allowed me to see what was going on, and sense what might be happening in a way that someone else, without the same history, could not. It is my hope that this put me in a position to make these interpretations speak loudly enough to be heard and understood by others. This writing is not about me, of
course, but of me (Smith, 1991), and in hermeneutics we can never separate ourselves from understanding.

Another strength I wish to draw attention to is not necessarily about the research itself, but rather about the therapeutic nature of hermeneutic work. It struck me during the interviews, how there seemed to be a therapeutic aspect to the conversations. Just by virtue of me asking about their experiences, I sensed that there was something therapeutic happening. The best example I can offer is Christina – the nine year old girl I discussed in Chapter 6 who spoke only two times in the first two thirds of the interview, then 13 times in the last third. Her parents’ comments to me about how talkative she was, and how unlike her it was to be like that, had me think that, in a way, that interview was therapeutic for her. Therapeutic in the sense of it giving her an opportunity to talk around her brother’s passing, versus “straight on.” For example, if I were to have asked her “how do you feel about your brother’s passing?” most likely she would have not known what to say or how to respond. However, asking questions about camp and her experiences there, allowed her to approach it obliquely, and perhaps an element of therapeutic-ness was achieved as a side effect of this hermeneutic research.

**Implications for future research.** I was left with several questions after my research that could be considered as future research questions. I questioned how families reconcile the two worlds of camp and the “real world” – one, a place of acceptance, fit, support, and community, and the other often described as the antithesis, at times. I found myself curious what that was like, going back and forth between these different environments, and believe that, by understanding how they accomplish this reconciliation, further support could be offered to these families.
It would also be interesting to understand the meaning of camp for homogenous groups within this community, for example bereaved families or newly diagnosed families. The families I interviewed were mixed, in terms of their placement in the childhood cancer experience, and while this was intentional, it might be interesting to understand more fully the experiences of families who are the most similar to one another.
Chapter Eleven: *Ordo ab Chao – Order from Chaos*

Camp seems chaotic. From the meals and activities, to the campfires and dances, it is loud, messy, and – to an outside observer – chaotic. There is order to this chaos, however, and what seems haphazard is purposeful, and hidden among the noise and chatter, lies a meaningfulness worthy of a second look, and a third. You cannot see or understand the meaning of camp simply by looking at it, or asking “what is camp like;” you have to feel it, taste it, experience it, talk to people, try things, participate, sit back and watch, and get dirt under your fingernails. It is an experiential event, addressing each of your senses, and with this comes a seductiveness because it makes you want it more, when you maybe did not even realize you wanted it in the first place.

Camp not only cares for the children with cancer and their families, it is also an incubator for the future generation of young adults that are leaders in the highest sense of the word – the counselors. These young men and women are our moral compasses, our lighthouses, our stars, and they are the people that are going to make profound differences in this world. I cannot emphasize enough how special these counselors are, and how they are truly there to help, and make a difference. They too, are loud, crazy, talented, and contribute to the chaos I observed, however, they are the backbone of camp, and without them, there would be no order from this chaos.

Cancer camp has reminded me that the more sophisticated the science of childhood cancer becomes, the more obvious it is that curing the disease is only half the battle. While a great deal of attention has been given to cure, more attention is needed in areas of care. As more and more children survive the disease, the pediatric oncology community is still discovering the long-term effects of treatment, and there are as many
psychosocial long-term effects of therapy as there are physical effects. Understanding the meaning of cancer camps for the child and family can help healthcare professionals and organizations like Kids Cancer Care refine and improve upon programs and services offered to these children and families, thereby improving upon the quality of care they receive. It is my hope that research, like this, can also be utilized to further legitimize the camp experience as one of significant benefit to children and families.

Like war, there are physical wounds from childhood cancer, but sometimes more importantly, there are psychological wounds that never go away. As one parent, whose son had been off treatment for 12 years, told me, “when you’re newly diagnosed you think that emotional pain will never go away… I started crying the minute I drove up [to camp] and I’ll probably cry again.” In some ways, camp is a reminder of the journey traveled, and a caution for those of us who care for these families to remember that because a child might be “cured” physically, does not mean they are “cured” mentally, psychologically, or spiritually. Gadamer (1960/1989) stated that “hermeneutic work is based on a polarity of familiarity and strangeness, and… the true locus of hermeneutics is this in-between” (p. 295). I have come to think of camp as a physical representation of this “in-between” to which Gadamer referred. “In-between” implies an openness, or space, and throughout many of my interpretations, the “space” at camp has played significantly into how to understand what was at play.

We are no longer able to approach this like an object of knowledge, grasping, measuring and controlling. Rather than meeting us in our world, it is much more a world into which we ourselves are drawn. [It] possesses its own worldliness and, thus, the center of its own Being so long as it is not placed into the object-
world of producing and marketing. The Being of this thing cannot be accessed by objectively measuring and estimating; rather, the totality of a lived context has entered into and is present in the thing. And we belong to it as well. Our orientation to it is always something like our orientation to an inheritance that this thing belongs to, be it from a stranger’s life or from our own. (Gadamer, 1994, p. 192)

Camp is a vast, open, empty space that is full of possibilities for new understandings, diminished suffering, and the telling of stories. Its empty space becomes filled with words, stories, emotion, laughter and play, kinship, fit, and community, and often, pain and suffering can be left there, to echo through the trees.
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Appendix A: Eligibility Requirements

For children with cancer and their families to be involved in the study, participants must:

- Be 6 years of age or older;
- Either have cancer, have had cancer, or be the parent, legal guardian, or sibling of a child who has, or has had, cancer;
- Have attended a cancer camp in the July/August 2012 season, or had a child who attended cancer camp in the July/August 2012 season;
- Be fluent in English.

For counselors to be involved in the study, participants must:

- Be employed as a counselor at Camp Kindle during the July/August 2012 season;
- Be 18 years of age or older;
- Be fluent in English.
Appendix B: Consent Form – Adult (Parent/Guardian)

**TITLE:** Understanding the Meaning of Children's Cancer Camps on Children and their Families

**SPONSOR:** Not applicable

**INVESTIGATOR:** Dr. Nancy J. Moules (Principal Investigator), Catherine Laing (Doctoral student)

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

**BACKGROUND**

Although cancer camps have been around since the 1970s very little research has been conducted around them. While these camps are designed to meet the needs of the whole family at each stage of the cancer experience, it is not well understood how children with cancer and their families interpret these experiences and what kind of meaning they derive from them.

Understanding the meaning of cancer camps to the child with cancer and his or her family can help health care professionals and organizations like the Kids Cancer Care Foundation of Alberta (KCCFA) refine and improve upon the programs and services offered to these families, thereby improving the quality of care they receive. Additionally, good quality research can be utilized by organizations like KCCFA (particularly with fundraising) to further legitimize the camp experience as not only a “feel good” experience, but as one that offers significant benefits to children and families. If children’s cancer camps were more fully understood, it is conceivable that they too could become viewed, or even targeted, as psychosocial interventions.

**WHAT IS THE PURPOSE OF THE STUDY?**

We know that most children who attend camp find it enjoyable, but we do not yet understand what kind of meaning camp has for children with cancer, their siblings, and their parents or caregivers. The purpose of this study is to explore with you, what your experiences of cancer camp have been and to understand more fully the meaning of these camps on children with cancer and their families.

**WHAT WOULD I (OR MY CHILD(REN)) HAVE TO DO?**

Your participation in this research will involve the following:
Attendance at an audiotaped interview with the doctoral student (may be as an individual, couple, or family). This interview will last from one to one and a half hours and involve only the people you have selected to be present (e.g. your spouse/partner, other children) and the interviewer. It will take place approximately 2 weeks after your child(ren) has/have returned home from camp in order to allow for some reflection. In this interview you will be asked about your experiences of your child(ren) attending cancer camp. It is expected that most participants will choose to conduct the interview in their homes, however if you would prefer a different location that will be accommodated. You are free to stop this interview at any time, take a break and resume. Alternatively, you can stop the interview and withdraw from the research. In any event, withdrawal from the study will incur no penalty to you.

**WHAT ARE THE RISKS?**

The purpose of this research is to more fully understand the meaning that children and their families find from cancer camp. In our conversations, we expect to talk mainly about these experiences of camp, however we also talk about things related to your child’s diagnosis, treatment, and prognosis, if you feel they are relevant.

There is a risk that these conversations may leave you feeling worse than before you participated.

In the event that you feel you need support to overcome these feelings, you can speak to the principal investigator who is an experienced family therapist. Should you (or the principal investigator) feel it is necessary; the researchers can refer you to a range of counseling services, some of which are free.

**WILL I OR MY CHILD(REN) BENEFIT IF I/WE TAKE PART?**

This study is not expected to have any direct benefit for you, however other people who have participated in this kind of research have said that talking about their experiences has been helpful and rewarding.

The information we get from this study may help us to understand more fully how children with cancer and their families understand and interpret their experiences at cancer camp and what kind of meaning this has for them. This is useful information for health care workers, pediatric oncology programs, and organizations like the Kids Cancer Care Foundation in order to plan, implement, improve or change programs offered to families with a child with cancer.

**DO I/WE HAVE TO PARTICIPATE?**

You are under no obligation to participate in this study.
Voluntariness and Withdrawal of consent

Your participation in this study is voluntary. You may withdraw from the study at any time without jeopardizing your relationship with the Alberta Children’s Hospital or the Kids Cancer Care Foundation of Alberta. You may withdraw from the study in a number of ways:
By contacting the principal investigator or doctoral student with your decision to withdraw;
By not attending, or canceling, your interview appointment;
By stopping an interview and advising the researcher/facilitator that you cannot stay, wish to leave and/or withdraw from the study.

In the event that you withdraw from the study, information from your interview will be destroyed and will not be used in the study.

WHAT ELSE DOES MY AND/OR MY CHILD(REN)’S PARTICIPATION INVOLVE?

Data from the interviews and conversation transcripts will be used to create possible understandings of the meaning of cancer camp for children and their families. The results of this study will first appear in the doctoral student’s dissertation, with a strong likelihood that individual papers will follow in relevant journals afterwards. Pseudonyms will be used to protect your anonymity.

There are no additional obligations or responsibilities accompanying participation in this study.

WILL I/WE BE PAID FOR PARTICIPATING, OR DO I/WE HAVE TO PAY FOR ANYTHING?

You will not be paid for participating in this study, nor will you incur any cost associated with your participation.

WILL MY/OUR RECORDS BE KEPT PRIVATE?

Access to records about you will be restricted to the research team only. All personal information and contact details will be securely kept on a password protected computer dedicated specifically to this study.

The audiotaped interviews and focus groups will be transcribed by the doctoral student. At no time will your identity be disclosed and pseudonyms will be used at all times. All research data will be stored in a locked filing cabinet at the University of Calgary, to which only the principal investigator has access.

The University of Calgary Conjoint Health Research Ethics Board will have access to the records.
SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time. If you have further questions concerning matters related to this research, please contact:

Dr. Nancy Moules (403) 220-4635

If you have any questions concerning your rights as a possible participant in this research, please contact The Director, The Office of Medical Bioethics, University of Calgary, at (403) 220-7990

Participant’s Name ___________________________ Signature and Date ______________

Investigator/Delegate’s Name ___________________________ Signature and Date ______________

Witness’ Name ___________________________ Signature and Date ______________

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.
Appendix C: Consent Form – Adult (Counselor)

**TITLE:** Understanding the Meaning of Children's Cancer Camps on Children and their Families

**SPONSOR:** Not applicable

**INVESTIGATOR:** Dr. Nancy J. Moules (Principal Investigator), Catherine Laing (Doctoral student)

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

**BACKGROUND**

Although cancer camps have been around since the 1970s very little research has been conducted around them. While these camps are designed to meet the needs of the whole family at each stage of the cancer experience, it is not well understood how children with cancer and their families interpret these experiences and what kind of meaning they derive from them.

Understanding the meaning of cancer camps to the child with cancer and his or her family can help health care professionals and organizations like the Kids Cancer Care Foundation of Alberta (KCCFA) refine and improve upon the programs and services offered to these families, thereby improving the quality of care they receive. Additionally, good quality research can be utilized by organizations like KCCFA (particularly with fundraising) to further legitimize the camp experience as not only a “feel good” experience, but as one that offers significant benefits to children and families. If children’s cancer camps were more fully understood, it is conceivable that they too could become viewed, or even targeted, as psychosocial interventions.

**WHAT IS THE PURPOSE OF THE STUDY?**

We know that most children who attend camp find it enjoyable, but we do not yet understand what kind of meaning camp has for children with cancer, their siblings, and their parents or caregivers. The purpose of this study is to explore with you, what your experiences of cancer camp have been and what, if any, changes or effects you have witnessed on the children who partake in these camps.

**WHAT WOULD I HAVE TO DO?**

Your participation in this research will involve the following:
Attendance at an audiotaped interview with the doctoral student (done in a focus group setting). This interview will last from one to one and a half hours and involve only yourself, the interviewer, and the other counselors from camp who have chosen to participate. It will take place during the week you attend camp, ideally towards the end of the week to allow for the most reflection on what your experiences and observations have been. You are free to stop this interview at any time, take a break and resume. Alternatively, you can stop the interview and withdraw from the research. In any event, withdrawal from the study will incur no penalty to you.

**WHAT ARE THE RISKS?**

The purpose of this research is to more fully understand the meaning that children and their families find from cancer camp. In our conversations, we expect to talk mainly about these experiences and observations of the children at camp, however we may also talk about things related to their diagnoses (e.g. treatment and prognosis), if you feel they are relevant.

There is a risk that these conversations may leave you feeling worse than before you participated.

In the event that you feel you need support to overcome these feelings, you can speak to the principal investigator who is an experienced family therapist. Should you (or the principal investigator) feel it is necessary; the researchers can refer you to a range of counseling services, some of which are free.

**WILL I BENEFIT IF I TAKE PART?**

This study is not expected to have any direct benefit for you, however other people who have participated in this kind of research have said that talking about their experiences has been helpful and rewarding.

The information we get from this study may help us to understand more fully how children with cancer and their families understand and interpret their experiences at cancer camp and what kind of meaning this has for them. This is useful information for health care workers, pediatric oncology programs, and organizations like the Kids Cancer Care Foundation in order to plan, implement, improve or change programs offered to families with a child with cancer.

**DO I HAVE TO PARTICIPATE?**

You are under no obligation to participate in this study.

Voluntariness and Withdrawal of consent

Your participation in this study is voluntary. You may withdraw from the study at any time without jeopardizing your relationship with the Alberta Children’s Hospital, Stollery
Children’s Hospital, or the Kids Cancer Care Foundation of Alberta. You may withdraw from the study in a number of ways:

- By contacting the principal investigator or doctoral student with your decision to withdraw;
- By not attending, or canceling, your interview appointment;
- By stopping an interview and advising the researcher/facilitator that you cannot stay, wish to leave and/or withdraw from the study.

In the event that you withdraw from the study, information from your interview will be destroyed and will not be used in the study.

**WHAT ELSE DOES MY PARTICIPATION INVOLVE?**

Data from the interviews and conversation transcripts will be used to create possible understandings of the meaning of cancer camp for children and their families. The results of this study will first appear in the doctoral student’s dissertation, with a strong likelihood that individual papers will follow in relevant journals afterwards. Pseudonyms will be used to protect your anonymity.

There are no additional obligations or responsibilities accompanying participation in this study.

**WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?**

You will not be paid for participating in this study, nor will you incur any cost associated with participating in this study.

**WILL MY RECORDS BE KEPT PRIVATE?**

Access to records about you will be restricted to the research team only. All personal information and contact details will be securely kept on a password protected computer dedicated specifically to this study.

The audiotaped interviews and focus groups will be transcribed by the doctoral student. At no time will your identity be disclosed and pseudonyms will be used at all times. All research data will be stored in a locked filing cabinet at the University of Calgary, to which only the principal investigator has access.

The University of Calgary Conjoint Health Research Ethics Board will have access to the records.
SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time. If you have further questions concerning matters related to this research, please contact:

Dr. Nancy Moules (403) 220-4635

If you have any questions concerning your rights as a possible participant in this research, please contact The Chair of the Conjoint Health Research Ethics Board, University of Calgary, at 403-220-7990.

Participant’s Name ___________________________ Signature and Date ___________________________

Investigator/Delegate’s Name ___________________________ Signature and Date ___________________________

Witness’ Name ___________________________ Signature and Date ___________________________

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.
Appendix D: Assent

**TITLE OF PROJECT:** Understanding the Meaning of Children's Cancer Camps on Children and their Families

**INVESTIGATORS:** Nancy Moules, RN PhD (403) 220-4635 and Catherine Laing, RN MN (403) 698-9493

**Why are we offering this study?**

We want to know what children and teens that have cancer think about cancer camps so that we can make sure these camps are the best they can be. We think that it is important to understand how and what you think of these camps as the first step to understanding in our research.

**What will happen during this study?**

During our meeting with you, we will ask you to help us understand more about what cancer camp means to you, what you like and don’t like, what kinds of experiences you have there, and if there is anything that is really interesting or special to you. Here is what is going to happen if you agree to join this study:

You will be asked to meet and talk with one of the researchers (your parents and brothers/sisters can be there too). We will ask you and your family about what it is like to have cancer, what it is like to go to camp, and ask you to share some of your stories from camp with us.

**Are there good things and bad things about the study?**

There are no problems that we know of that could hurt you by being part of this project. However, you might find that answering the questions we ask you are boring or uncomfortable at times.

**Who will know about what I do during this study?**

If you participate in this study, your name and address will not be given to anyone. Only the staff working with this study will know what you said during the project.

**Can I decide if I don't want to join this study?**

It is okay if you do not want to be part of this research project. Nobody will be angry or upset if you do not want to be in the study. If you say yes now but change your mind later, you can tell us, and that will be okay too. Your mother or father is also reading information about this project. They will talk to you about it. Ask them any questions that you do not understand from what you have read or heard. They will help you to understand. Please also ask us any questions, and we will also help you to understand.
**Assent:**

I was present when ___________________ read this form and said that he or she agreed or assented, to take part in this study.

_____________________________
Name of person who obtained assent

_____________________________
Signature

_____________________________
Date
Appendix E: Sample Interview Questions

Kids (with cancer and siblings)
1. Experiences at camp that were most impactful. Why? What was it about these experiences?
2. In what ways do you feel different after camp? Why do you think that is? Do you think anyone else has noticed that you are different and if so, what have they noticed?
3. What do you think you might have learned from camp that you couldn’t have learned elsewhere?
4. What are some of the best things about camp?
5. Was there anything you didn’t like?
6. What would be the most important thing you think I should know about camp?
7. Would you tell another kid that they should come to camp? If someone didn’t know if they wanted to or not, what would say to them? How would you convince them?
8. If some grownup had a bunch of money and they were wanted to donate it to camp, and they asked you why they should, what would you say to them?
9. Do you think camps for kids with cancer are different than other camps and if so, how are they different?
10. In what ways do you think camp was different for you and you sibling?

For parents:
1. What kinds of changes have you noticed in your child since returning from camp? What do you attribute these to? Can you give me some examples?
2. What was it like for you to have your child away at camp?
3. What has been the biggest difference in your child since camp? What about your family? Who in the family seems most different?
4. What do you think is most important thing that other parents of children with cancer who are considering whether to send their kids to camp should understand? If a parent asked your advice about sending their kid, what reasons would you give them?
5. What is most important that the public understands about kids cancer camps?
6. Do you think camps for kids with cancer are more, less, or about the same important than camps for every kid? Say more about your response.

For counselors:
1. What do you think it is about camp that affects these kids?
2. How were you affected or changed by camp?
3. What kinds of changes did you notice in some kids? What do you think differentiates kids that you noticed changes in, versus kids in whom you didn’t see any changes?
4. For someone that didn’t know anything about working with these kids at camp, how would you describe it?
5. For people that were considering donating money to support camp what would you tell them?