# "It's not Just Camp!": Understanding the Meaning of Children's Cancer Camps for Children and Families

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#### **Abstract**

The purpose of 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 5 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: the healing and developmental power of play, finding acceptance and fit, grief as something to live with versus "get over," storytelling as a means of reshaping and understanding traumatic experiences, and the solidarity of the community as one that creates intense, healing bonds. Children's cancer camps, we conclude, should be considered a necessity, versus a luxury, and could 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 separateness of camps from hospital programs.

#### **Keywords**

cancer camps, hermeneutics, play, acceptance

Almost anyone who works with children with cancer could attest to the excitement most kids have about cancer camp. Rooted in outdoor education and adventure programming, cancer camps arose in the 1970s as a way for children and their families to escape the severity of cancer treatment (Bluebond-Langner, Perkel, Goertzel, Nelson, & McGeary, 1990; Kids Cancer Care [KCC] Foundation of Alberta, 2012). These camps, like other therapeutic camping programs (eg, Camp Huff n' Puff [asthma], Camp Maska [nephrology]) are specifically designed to meet the needs of children and families at all stages of the disease trajectory (KCC Foundation of Alberta, 2012); utilization of these camps has grown steadily since their inception (Canadian Association of Pediatric Oncology Camps, 2012). While the popularity and utilization of cancer camps appear to be growing, very little is understood about why these camps play such an important role for many cancer families. Our intent in this article is to summarize the findings of the first author's philosophical hermeneutic doctoral research around understanding the meaning of children's cancer camps for the child with cancer and the family. While this article offers a summary, it is worth noting that the full analysis of each finding has been published as distinct articles.

# **Study Objective**

The research question for this study was "How might we understand the meaning of children's cancer camps on children and their families?" Interest for this topic came from both authors' personal experience nursing in the pediatric oncology setting and watching most children and families' excitement of, and effect from, cancer camps. Additionally, lack of research—particularly qualitative research—around children's cancer camps spoke to a lack of understanding of the meaning of these camps and the role they play in the lives of children with cancer. At the heart of this study was an attempt to understand why: Why was camp so meaningful for these children and families, and furthermore, why does it matter?

# Background Information and Literature Review

While significant anecdotal information related to cancer camps exists, very little research has been conducted in this area. A literature search in relevant databases (nursing, education, family, psychology) produced only 16 studies dealing specifically with cancer camps. Measurable constructs such as self-concept (Benson, 1987; Kessell, Resnick, & Blum, 1985; Murray, 2001),

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psychosocial impact (Packman et al., 2008; Wellisch, Crater, Wiley, Belin, & Weinstein, 2006), and medical knowledge (Bluebond-Langner et al., 1990; Carpenter, Sahler, & Davis, 1990) have been examined, most indicating an undetectable, neutral, or marginal effect from camp. Previous studies have been predominantly from the quantitative paradigm, with the exception of two mixed-methods studies (Bluebond-Langner et al., 1990; Bluebond-Langner, Perkel, Goertzel, Nelson, & McGeary, 1991). To the best of our knowledge, no qualitative research had been conducted related to children's cancer camps prior to this study.

While a paucity of research exists related to cancer camps, there has been significant research in the area of therapeutic camping (eg, Mishna, Michalski, Cummings, 2002; Walker & Pearman, 2009; Welch, Carlson, Larson, & Fena, 2007). Therapeutic camping is a purposeful approach to recreation, where outdoor adventure is used as the primary means to achieve therapeutic goals, often with vulnerable or marginalized populations (Davis-Berman & Berman, 1989). Perhaps unsurprisingly, most research related to therapeutic camping programs is suggestive of positive, albeit difficult to measure, effects on the children for whom they are targeted. Additionally, a meta-analysis of outdoor education programs suggested that self-concept, academic performance, leadership, interpersonal skills, personality, and adventuresomeness were all mildly positively correlated to outdoor programming (Hattie, Marsh, Neill, & Richards, 1997). The uniqueness of childhood cancer, however, presents unique challenges, differences, and outcomes that must be considered with respect to cancer camp (Laing & Moules, 2013). We believe this to be the first qualitative study undertaken in search of understanding the *meaning* of these camps to children with cancer and their families.

# **Research Design**

## Method

This research was conducted in the tradition of philosophical hermeneutics, defined as the art, tradition, and practice of interpretation (Gadamer, 1960/1989) as developed by Hans-Georg Gadamer (1900-2002). It is a reflective, dialogic inquiry, concerned with understanding the world and the various forms in which understanding is manifested (Benner, 1994; Chesla, 1995; Moules, 2002; Grondin, 1994, 1995; Gadamer, 1960/1989, 1976; Koch, 1996; Morse & Field, 1995; Smits, 1997). Hermeneutics, often categorized under the umbrella of phenomenology, is concerned with "our entire understanding of the world . . . and all the various forms in which this understanding manifests itself" (Gadamer, 1976, p. 18). In other words,

hermeneutics is interested in understanding human experiences. Moules, Laing, McCaffrey, Tapp, and Strother (2012) described the natural fit of hermeneutics with pediatric oncology, in that the experience of cancer in a child and adolescent and their families is an interpreted experience, "uniquely borne by families who received the diagnosis of what is often described as a 'worst nightmare' moment come true" (p. 121). Health care professionals, Moules et al. (2012) argued, are obligated to understand the many facets of this experience in order to provide the most generative, comprehensive, and compassionate care.

As a research method, hermeneutics offers significant insight into complex phenomena like childhood cancer that has direct implications for practice. It offers a way to know and understand the world and, thus, the topic (Gadamer, 1960/1989). Childhood cancer is a complex disease on many levels. Psychosocially, this complexity cannot be adequately, or solely, measured through traditional quantitative approaches. "There are no measures that respectfully articulate what this life event asks of family members, children, caregivers, and health care professionals" (Moules et al., 2012, p. 121). Hermeneutics offers an opportunity by which to understand some of this complexity.

# Recruitment of Participants

The study participants for this research project included children and their families who attended the KCC Foundation's Camp Kindle in the summer season of 2012. Families were initially contacted about participation in this study by the KCC family liaison and then, on showing interest, were contacted by the researcher. A total of 6 families (20 participants in total) were interviewed (Table 1). Most families interviewed as a family unit; however, in 2 instances, the interviews were done with the parent(s) first and the child(ren) afterward (with the parents in attendance), due to scheduling issues. Of the 6 families who participated, 1 family was bereaved, 2 had children still receiving active therapy, and 3 had children who had completed therapy. All interviews took place within 1 month of camp attendance.

Additionally 5 camp counselors were recruited, and interviewed in a focus group setting, to bring further understanding to this topic (Table 2). Counselors were initially contacted about participating in this study by the camp coordinator, then followed up with by the researcher on indicating interest. The focus group took place on a Sunday, after children and families left camp.

In hermeneutic research, like other qualitative research methods, measures of "power" and random sampling are not used (Koch, 1996; Morse & Field, 1995; Moules, 2002). The best individuals to include in a hermeneutic

Table I. Participant Characteristics: Families.

Participants	Family structure	Present at interview	Status	Original diagnosis
Family A	Mother	Mother, child 1, child 2, child 3	Child 2 is cancer survivor × 10 years; 5th time at camp	Wilms's tumor
	Child 1: 9 years			
	Child 2: 11 years			
	Child 3: 14 years			
Family B	Mother	Mother, father, child 1, child 2	Child 2 currently on active treatment; 3rd time at camp	Leukemia
	Father			
	Child 1: 5 years			
	Child 2: 8 years			
Family C	Mother, father	Mother	Child 2 off therapy × 5 years; 4th time at camp	Brain tumor
	Father			
	Child 1: 10 years			
	Child 2: 12 years			
	Child 3: 14 years			
Family D	Mother	Mother, father, child 2, child 3, child 4, child 5	Bereaved family. Child I passed away from cancer 6 years ago (age 2 years); 6th time at camp	Leukemia
	Father		(3 / /-	
	Child I: deceased			
	Child 2: 9 years			
	Child 3: 12 years			
	Child 4: 15 years			
	Child 5: 17 years			
Family E	Mother	Mother, father, child (age 7)	Child 2 had just completed active therapy; 2nd time at camp	Brain tumor
	Father			
	Child 1: 5 years			
	Child 2: 7 years			
Family F	Mother	Mother	Child 2 off therapy × 1 year; 3rd time at camp	Brain tumor
	Father		-	
	Child 1: 9 years			
	Child 2: 10 years			

inquiry are ones that can most inform understanding of the topic (known as purposive sampling) as the researcher's aim is to elicit a richness of data through the experiences of the participants.

#### **Data Generation**

With children and families, after informed written consent was obtained, semistructured interviews at the location of the participants' choosing were conducted (most occurred in the participants' homes). Guiding questions (Table 3), generated before the interview, were used. Typically in hermeneutic research, these questions do not have to be asked in all interviews if the direction of the conversation is led elsewhere (Moules, McCaffrey, Field, & Laing, in press). Instead, they serve to orient the

interviewer to the topic and are formatted with careful attention to context, settings, explanations, consents, audiotaping, engagement, process checking, and closure (Moules et al., in press). Unlike other qualitative methods, hermeneutic research does not employ member checking as a part of the data generation process; however, follow-up or probing questions are often used if the interviewer seeks more information or clarification around the subject matter. Each interview took 1 to 1½ hours and was recorded and transcribed for ongoing analysis. Basic demographics of the participants were collected, and field notes were written after each interview, recording contextual details to assist with the data analysis. Counselors were interviewed in a focus group setting, with the interview taking approximately 1.5 hours. This too, was recorded and transcribed for analysis, and basic

Table 2. Participant Characteristics: Counselors.

Participant	Age, years	Comment
I	22	Survivor of childhood cancer; 7 years as camp counselor
2	18	Sibling of childhood cancer survivor; second year as camp counselor
3	21	Second year as camp counselor
4	21	Second year as camp counselor
5	20	First year as camp counselor

demographics of the counselor participants were obtained. In addition, the first author attended camp as a participant observer on 8 separate occasions, which generated further data that were incorporated into the analysis.

## Analysis and Interpretation of Data

Unlike other qualitative methods that employ data coding or themes, or seek to develop theories, capture essences, or explain a phenomenon, the tradition of hermeneutics is about understanding, and understanding and interpretation are synonymous. Data analysis, in hermeneutics, is interpretation, and arriving at interpretations is a rigorous practice with "a communal, reflexive, multilayered quality that brings together knowledge, information, conversation, experience, and data to join with intuition and understanding" (Moules et al., 2012, p. 121). Transcripts are formatted with line-by-line numbering and wide right-hand margins for notes. They then become working documents, intended to be read and reread, written on, and marked, becoming a concrete work of dialogue (Moules et al., in press). Together with listening to the recordings, reading, and annotating transcripts, beginning interpretations and conjectures are captured in memo format. Akin to memoing or journaling done in other qualitative traditions only in the sense of being an intermediate step, interpretive memos, as they are often called in hermeneutics, serve the purpose of capturing and tracking ideas, both for the researcher's own use and as part of an audit trail to demonstrate rigor in the research (Moules et al., in press). Fully developed interpretations take form as the researcher considers all the data in parts and wholes (termed the hermeneutic circle), and considers, or reconsiders, the taken-for-granted assumptions about a topic, while attempting to uncover something new about it—to try and see it differently. This process is uniquely distinguishable from other qualitative methods, as hermeneutic research resists thematic reductionism as a goal of analysis, allowing instead for the recognition of extraordinary occurrences and exceptional views to emerge from the data (Moules et al., in press).

Table 3. Sample Questions.

Kids (with cancer and siblings)

- I. 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 (or would you)?
- 8. If some grown-up 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?

#### **Parents**

- I. 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.

#### Counselors

- I. 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?

Gadamer's (1960/1989) philosophy of understanding text guides data analysis not only by movement in and out of the data but also via a concept he termed, the *fusion of horizons* (p. 302). The fusion of horizons, or the coming together of 2 or more understandings of the topic, coupled with the genuine curiosity of the researcher and desire to understand the topic in a new way, helps further the understanding of the topic (Binding & Tapp, 2008; Koch, 1996). Interpreting or understanding the data, in other words, involves the horizon, or understanding, of the interpreter and the historical horizon, or context, into which one places oneself when trying to understanding to occur.

The remainder of this article is related directly to the first author's findings about the meanings of children's cancer camps for the child with cancer and the family. It is appropriate that at this point hermeneutics, as a topic, needs to disappear into the background (Moules, 2002) while the topic of cancer camps take center stage. The reader will notice a change in the style, tone, and cadence of the writing, as well as the type of language used, and as such, a mental "switching of gears" is required. In the next section, we 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.

# **Interpretive Analysis**

Five predominant findings came from this research and will be summarized below: play, acceptance, grief, story-telling, and community. Should the reader want further information, or access to the full analysis in the publication, the citation is provided.

## In Play, At Play (Laing, 2012)

Perhaps synonymous with camp is the thought of fun and play, and it would not surprise anyone to learn that an enormous amount of play happens at camp. From the formal interviews to the field observations, it was obvious that for the children, camp is about play. From the moment they wake up to the moment their heads hit the pillow, they are engaged in some kind of play, however, it is not the finding *that* children play at camp, but rather *why* it is important.

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<sup>1</sup> 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 professionals 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 (Laing, 2012). 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 (eg, central venous catheters) that require care and attention. Summer camp—a "rite of passage" for many kidswould 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 research community. "Play, more than any other activity, fuels healthy development of children—and, the continued healthy development of adults" (Perry, Hogan, & Marlin, 2000, p. 2). Children's 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 often 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 also 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.

Playlessness. 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 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. Camp, I suggest, offers the antidote for this; it is all about the play (Laing, 2012).

# The Island of Misfit Toys (Laing & Moules, 2013)

Um, I know this sounds really weird but sometimes I think of camp as the Island of Misfit Toys cause there's all something—[they'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 [nickname] (laughs). I mean, outtrip [an overnight camping experience], like he was just telling a story and showing off [his stump] 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)

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; http://www.merriam-webster.com/dictionary/oasis), 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 reknow, their experiences with childhood cancer and allows them the opportunity to process traumatic events and emotions differently.

The acceptance experienced at camp allows children and families to experience misfit differently, not as beings that "fit poorly" (Merriam-Webster; http://www.merriam-webster.com/dictionary/misfit) in their environment, but rather as beings that are differently suited to their environments.

# A Way to Understand Grief Differently (Laing & Moules, in Press)

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)

When we consider that grief can be understood as an experience that changes over time but is never completed (Silverman & Klass, 1996), and yet society treats grief as an experience one does, or should indeed, "get over," it is not surprising to understand how families experiencing grief might find tension in this dichotomy (Laing & Moules, in press). At camp, families are not expected to get over their grief; in fact, I offer that they are given space in which to understand their grief differently. One bereaved 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. 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—is ritualized, and sacred, for families.

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)

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, cited in Summers-Effler, 2006) 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 (ie, 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, providing direction and validation to the search for meaning amid grief. Through rituals, the grieving are confronted with new ways of knowing and may come to understand the world differently.

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, often, to be understood differently (Laing & Moules, in press).

# Stories From Cancer Camp (Laing & Moules, 2014b)

- 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 fingernetting 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!

There are endless stories told at camp, and of camp. 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 convey 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).

In telling stories, children make sense of their lives (Widdershoven, 1993) and are often able to reprocess 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 reenter the "real" world. Sharing of stories is another way in which parents, too, benefit from the camp experience. The stories of parents are filled with gratitude, and camp provides parents the opportunity to feel gratitude and express gratefulness.

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)

It is by the telling and retelling of their stories that parents and children define, or redefine, the experience of childhood cancer and may come to understand its meaning differently (Laing & Moules, 2014b).

# A Sense of Community, a Sense of Family (Laing & Moules, 2014a)

Central to the idea of community, is the concept of belonging to something, and this community of childhood cancer is not one that people enter willingly, yet once inside, appears to offer a profound sense of belonging.

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. (Parent)

Gadamer (1960/1989) spoke of *sensus communis*, its literal translation from Latin meaning "common sense," however not in the regular, everyday 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). 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 this idea of sensus communis. These families share a "common" sense with one another—a sense acquired only by those who share the experience of having a child with cancer.

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)

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,

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)

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 (Laing & Moules, 2014a). The community of camp exposes children to many others who are different from themselves (eg, 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.

# **Discussion and Implications**

Camp fulfills different needs for different families, but one commonality in this study was that a tremendous amount of healing occurs at camp. The concepts of play, acceptance and inclusion, grief, storytelling, and community all speak to the different ways in which this healing may occur. Depending on where the child and family are in the cancer experience, this healing is different for everyone. For one parent, it came 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 one child, it came by way of finding acceptance, and ultimately pride, for his amputated leg. For a bereaved family, their son now 6 years deceased, their healing seemed to happen by way of giving back to this community and helping others.

While previous research has mainly focused on the measurement of certain constructs (eg, medical knowledge, psychosocial impact), this research has added a more robust understanding around the meaning of camp for children and families. Said differently, it contributes to knowing why and what makes camp so important for many children with cancer and their families. Understanding the "whys and whats" of cancer camp can be important for future researchers to identify areas for further study and for camping programs in terms of program development. Additionally, this research can be used by philanthropic organizations that fund cancer camps to further legitimize the camp experience as not only a "feel-good" experience but also one that offers significant benefits to children and families. The outcomes from this research suggest that children's cancer camps should be thought of as a necessity versus a luxury and could even serve as a psychosocial intervention for some

children and families. Future research could further the evidence around this, and pediatric oncology programs may one day target cancer camps as an intervention used to improve psychosocial health and outcomes versus simply an enjoyable experience for the child.

There are current challenges to the sustainability of cancer camps, the most significant being the way camps are often 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; and many other governments in North America and worldwide) 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. Cancer camp, it could be argued, and would be further substantiated by future research in this field, could be 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 health care 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 health care 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, health care. Similarly, if philanthropic organizations that host these camps did not need to rely on public donations to fund the children's cancer camps each year, the scope of funding opportunities could broaden, and support for other programs related to improving the quality of care of children and families of childhood cancer could increase, potentially leading to improvement in other outcomes related to the care of these families.

### **Conclusion**

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)

While a vast improvement in childhood cancer survival rates has occurred over the past 30 years (Canadian

Association of Pediatric Oncology Camps, 2012), it is not without a cost. Lifelong side effects, both physical and psychological, occur in as much as 70% survivors of childhood cancer (Children's Oncology Group, 2014), leading to increased health care resource utilization from this cohort and their families. As health care costs rise and outcomes improve, innovativeness around the way care is delivered to these children and families takes on paramount importance. Cancer camp, as shown by this research, might be considered a care delivery method in this approach.

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. There are as many kinds of healing as there are families that attend camp, and while one could never know them all, their stories all speak to healing themselves, and others, and finding "the happy place in all of that darkness."

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