Stories from Cancer Camp:
Tales of Glitter and Gratitude

Catherine M. Laing¹ & Nancy J. Moules¹

Abstract

Each year in Canada, approximately 1400 children and adolescents under the age of 20 are diagnosed with cancer. It is well recognized that childhood cancer affects the entire family, and innumerable challenges accompany this diagnosis. In recognition of the challenges that accompany this disease, cancer camps started in the 1970s to help children and their families escape the rigidity and severity of cancer treatment. Very little is known about how camps affect these families, and to that end, a philosophical hermeneutic study was conducted to understand the meaning of children’s cancer camps for the child with cancer and the family. Six families were interviewed to bring understanding to this topic, and while the research included findings related to the concept of play, fit and acceptance, grief, and community, this paper will detail the finding related to storytelling and the reshaping of experiences that happens by virtue of being at camp.

Keywords

hermeneutics, storytelling, cancer camp, pediatric oncology

In response to the challenges and stress of childhood cancer, children’s cancer camps arose in the 1970s as a way for children and their families to escape the rigor 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, including survivorship or bereavement (Kids Cancer Care Foundation of Alberta, 2012). Currently in Canada, eight cancer camps provide service to 5,252 children and their families (Canadian Association of Pediatric Oncology Camps, 2012), and as more children are surviving childhood cancer, the need for specialized camps and community

¹ University of Calgary

Corresponding Author:
Catherine M. Laing
Email: laingc@ucalgary.ca
programs continues to grow (Laing & Moules, 2013).

Our intent in this paper is to describe one of 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 the doctoral thesis included findings related to: the concept of play at cancer camp (both philosophically and theoretically) (Laing, 2012); the fit and acceptance that children and families find at camp (Laing & Moules, 2013); the solidarity of the community – the “camp family” – as one that creates intense, healing bonds (Laing & Moules, in press); and grief as something that children and families experience differently, this paper will detail the finding related to storytelling, both by children and parents, as a means of re-shaping and understanding traumatic experiences.

Background Information and Literature Review

While very few studies related to children’s cancer camps have been conducted, there are many anecdotal accounts of the benefit of cancer camps. A search of nursing, education, family, and psychology databases yielded 16 studies pertaining specifically to children’s cancer camps; in other words, very little is understood about the effects of cancer camps on the child and family (Laing & Moules, 2013).

Of the available literature, topics such as self-concept (Benson, 1987; Kessell, Resnick, & Blum, 1985; Murray, 2001), psychosocial impact (Packman et al., 2008; Wellisch, Crater, Wiley, Belin, & Weinstein, 2006), medical knowledge (Carpenter, Sahler, & Davis, 1990; Bluebond-Langner et al., 1990), and other measurable constructs have been examined. Most studies report either a neutral (or undetectable) effect from camp, or a marginal improvement on the construct in question, most relating this to self-reported limitations of insufficiently powered sample sizes and lack of control groups.

More research has been conducted in the fields of outdoor programming and therapeutic camping – a term used to describe a purposeful approach to recreation, often involving marginalized or vulnerable populations. 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). Recently, certain childhood disease groups have organized camps for children specific to their disease (e.g., Camp Huff n’ Puff [asthma], Camp Maska [nephrology]). There has been a significant amount of research pertaining to these therapeutic camps (e.g., Mishna, Michalski, & Cummings, 2001; Walker & Pearman, 2009; Welch, Carlson, Larson, & Fena, 2007), with most researchers concluding that these camps have a positive effect on the children for whom they are targeted. Childhood cancer, however, is a unique disease, and with it comes unique challenges, differences, and outcomes that must be considered with respect to camp (Laing & Moules, 2013). To the best of our knowledge, this was the first qualitative study undertaken in search of understanding the meaning of these camps to children with cancer and their families.
Research Design

Method

The research question for this study was, “How might we understand the meaning of children's cancer camps on children and their families?” This research was guided by philosophical hermeneutics, defined as the art, tradition, and practice of interpretation (Gadamer, 1960/1989), as developed by Hans-Georg Gadamer (1900-2002). Hermeneutics is interested in human experience, and offers a way to know and understand the world and, thus, the topic (Gadamer, 1960/1989). It is a sophisticated method of research and approach to understanding within the human sciences, and, particularly in health care, hermeneutics has been shown to have invaluable applied utility (Moules, McCaffrey, Morek, & Jardine, 2011). Hermeneutics helps us make sense of the particulars (Moules, 2002) and arrive at deeper understandings of how children’s cancer camps, for example, impact children with cancer and their families. Hermeneutics, as an approach to research, is an interpretive methodology, a reflexive inquiry, where the researcher is not considered a separate entity, or non-influencing factor, from that which she/he is researching. The “data,” Ricoeur (1981) offered, never stand alone as their meaning depends on the researcher and the reader. Hermeneutics seeks to understand rather than explain.

Recruitment of Participants

The appropriate individuals to include in a hermeneutic inquiry are ones that can best inform understanding of the topic (known as purposive sampling) as it is the researcher’s aim to elicit a richness of data through the experiences of the participants (Laing & Moules, 2013). The participants for this research included children with cancer and their families who attended the 2012 Kids Cancer Care (KCC) Foundation’s Camp Kindle in the summer camping season. Seven families were contacted about participation in this study by the KCC family liaison, with 6 families (Table 1) agreeing to participate (equaling 19 participants in total). Upon stating their agreement to the family liaison, the interested families were then contacted by me (first author) to further explain the study. It is worth noting here for clarity, that for many families, cancer camp is not a one-time event. Kids Cancer Care (like similar philanthropic organizations) offers weekend camps and other events throughout the year, in hopes to engage, support, and connect children with cancer and their families.

Data Generation

After informed written consent was obtained, I conducted semi-structured interviews at the location of the participant’s choosing (three interviews occurred in the participants’ homes, one interview was at a public library, one was at a local recreation complex, and one was at a coffee shop). Each interview took 1 to 1 ½ hours, and was recorded and transcribed for ongoing analysis, and basic demographics of the participants were also obtained. After each interview, field notes were written to capture contextual details to assist with the data analysis. All interviews took place within one month of camp attendance. In addition, I attended camp as a participant observer on 6 occasions throughout the 2012 summer camping season which generated further data that was incorporated into the analysis.
Table 1

**Participant Characteristics**

<table>
<thead>
<tr>
<th>Participants</th>
<th>Family Structure</th>
<th>Present at Interview</th>
<th>Status</th>
<th>Original Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family A</td>
<td>Mother</td>
<td>Mother, child 1, child 2, child 3</td>
<td>Child 2 is cancer survivor x 10 years; 5th time at camp</td>
<td>Wilms' tumor</td>
</tr>
<tr>
<td>Family A</td>
<td>Child 1: 9y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family A</td>
<td>Child 2: 11y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family A</td>
<td>Child 3: 14y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family B</td>
<td>Mother, Father</td>
<td>Mother, Father, child 1, child 2</td>
<td>Child 2 currently on active treatment; 3rd time at camp</td>
<td>Leukemia</td>
</tr>
<tr>
<td>Family B</td>
<td>Child 1: 5y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family B</td>
<td>Child 2: 8y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family C</td>
<td>Mother, Father</td>
<td>Mother</td>
<td>Child 2 off therapy x 5 years; 4th time at camp</td>
<td>Brain tumor</td>
</tr>
<tr>
<td>Family C</td>
<td>Child 1: 10y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family C</td>
<td>Child 2: 12y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family C</td>
<td>Child 3: 14y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>McMahon Family</td>
<td>Mother, Father</td>
<td>Mother, Father, child 2, child 3, child 4, child 5</td>
<td>Bereaved family. Child 1 passed away from cancer 6 years ago (aged 2 years); 6th time at camp</td>
<td>Leukemia</td>
</tr>
<tr>
<td>McMahon Family</td>
<td>Child 1: deceased</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>McMahon Family</td>
<td>Child 2: 9y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>McMahon Family</td>
<td>Child 3: 12y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>McMahon Family</td>
<td>Child 4: 15y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>McMahon Family</td>
<td>Child 5: 17y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family E</td>
<td>Mother, Father</td>
<td>Mother, Father, child (age 7)</td>
<td>Child 2 had just completed active therapy; 2nd time at camp</td>
<td>Brain tumor</td>
</tr>
<tr>
<td>Family E</td>
<td>Child 1: 5y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family E</td>
<td>Child 2: 7y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family F</td>
<td>Mother</td>
<td>Mother</td>
<td>Child 2 off therapy x 1 year; 3rd time at camp</td>
<td>Brain tumor</td>
</tr>
<tr>
<td>Family F</td>
<td>Child 1: 9y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family F</td>
<td>Child 2: 10y</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Analysis and Interpretation of Data**

Data analysis is synonymous with interpretation in the tradition of hermeneutics (Moules, 2002; Moules, Laing, McCaffrey, Tapp, & Strother, 2012), and arriving at interpretations is a rigorous practice bringing together knowledge, information, conversation, experience, and data. To understand the process of how interpretations are developed, the concepts of fusion of horizons and the hermeneutic circle merit discussion. The fusion of horizons, where “horizon” is a metaphor for how reality is perceived and interpreted (Austgard, 2012), is the coming together of more than one understanding of the topic, coupled with the curiosity and desire of the researcher to understand the topic in a new way (Binding & Tapp, 2008; Koch, 1996). The hermeneutic circle is the metaphorical representation of understanding the whole by grasping its parts and by comprehending the meaning of the parts, by considering the whole (Crotty, 1998). This movement in and out of “parts and wholes” is circular, recursive, and involves the researchers as an integral part of the circle. The hermeneutic circle invites the researcher 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, extensive readings and re-readings, reflection, dialogue, and challenging taken-for-granted assumptions allows for consideration of that which might not have been initially visible, and enhances the understanding of the topic (Laing & Moules, 2013; Moules, 2002).

The remainder of this manuscript is related directly to the findings around the concept of storytelling that occurs at children’s cancer camps. It is appropriate that, at this point, hermeneutics, as a topic, will disappear into the background while the topic of storytelling takes center stage (Moules, 2002). 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

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.

I heard stories from children during the research interviews but even more so at camp. On the way to and from activities, during activities, during mealtimes, during “quiet time” – stories filled any potentially quiet and empty space of camp. Children told each other stories, they told the counselors stories, they told me stories, and at times, frankly, it was overwhelming and consuming for my quiet, adult nature, but the more I thought about it and watched what was happening, the more I was able to see how this normal, unassuming occurrence was serving a very important role. Because, as Stevens (1981) said, “Children never get to the point, they surround it. The importance of the point is the landscape of it” (cited in Jardine & Clandinin, 1987, p. 477).
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; in other words, it is in their stories where the value lies. So common were their stories, that I almost missed them. I almost did not appreciate their importance because they were so pervasive, much like when something is so common one stops “seeing” it after a while. The stories of these children were not “just” stories; there was a lot happening in these stories, however in order to understand the profundity of them, one must first appreciate the tradition of storytelling.

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 (Bowlles, 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 and formed 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:

---

1 The McMahon family has asked me to refer to them by their real names instead of using pseudonyms.
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 died.
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 a 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, wrote 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.

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. 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 proce-
dures 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 sub-consciously) 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) noted 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.

**Bios**

Dr. Catherine M. Laing is an Assistant Professor in the Faculty of Nursing at the University of Calgary.
Dr. Nancy J. Moules is a Professor in the Faculty of Nursing at the University of Calgary. She also holds the Alberta Children’s Hospital Foundation and Research Institute Nursing Professorship in Child and Family Centred Cancer Care.

Acknowledgement

This doctoral study was funded by a generous scholarship from the Alberta Children’s Hospital Foundation to which the authors express immense gratitude.

References


