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The Island of Misfit Toys

Catherine M. Laing & Nancy J. Moules

Abstract

A philosophical hermeneutic study was conducted to understand the meaning of children's cancer camps for children with cancer and their families. Six families and five camp counselors were interviewed in order to bring understanding to this topic. While the research included findings related to the concept of play at cancer camp (both philosophically and theoretically); 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, this paper details the finding related to the children and families experience of finding acceptance and fit at camp.

Keywords

children's cancer camps, hermeneutic research, pediatric oncology, pediatric psychosocial oncology

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, & McGear, 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 three years (Canadian Association of Pediatric Oncology Camps, 2012). As more children are surviving childhood cancer, the need for specialized camps and community programs continues to grow.

Our intent in this paper is to describe one of the findings of the first author's doctoral

Corresponding Author:
Catherine M. Laing RN PhD
Email: laingc@ucalgary.ca

research study that invoked philosophical hermeneutics as an approach to understand the meaning of children's cancer camps for the child with cancer and the family. Six families and five cancer camp counselors were interviewed in order to bring understanding to this topic. The doctoral thesis research included findings related to: the concept of play at cancer camp (both philosophically and theoretically); 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. In this paper, we will detail the specific finding related to the children and families experience of finding acceptance and fit at camp.

Interpretive Analysis

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 one separates *mis* from *fit*, and examines 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. At cancer camp, 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 un-accepted in the “real world.”¹

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, Attention Deficit Hyperactivity Disorder), 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, Zeller, & Noll, 2009, p. 303). Establishing relationships with peers is a major developmental task of preadolescence and adolescence (Sullivan, 1953) and provides 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

¹ 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.

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 (e.g. increased self-confidence and self-esteem, quality of life, etc.) 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 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 were captured in other ways throughout this research. 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.

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. (Don, 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, antidepressants). 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 at cancer camp – are for some individuals more power-

ful 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.

Biographies

Catherine M. Laing, RN, PhD is an Assistant Professor in the Faculty of Nursing at the University of Calgary.

Nancy J. Moules, RN, PhD is a Professor in the Faculty of Nursing at the University of Calgary. She also holds the ACHF/ACHRI Nursing Professorship in Child and Family Centred Cancer Care.

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