

I do not wish to return only to the original research question, rather I wish to return to it in the context of the title of this dissertation: *It's not just camp*. The research question and title are connected, because by understanding *why* it is not “just camp,” we start to understand the meaning of cancer camp for the child and family. Over the past five chapters, I have offered my interpretations in hopes of furthering understanding around this topic, of understanding why camp is not just camp, however I do not believe that, in hermeneutics, the question is ever fully answered. Life is messy, as Jardine (2006) noted, and somehow we lose something that is important when we try to flatten it out and make it orderly. Therefore, as I return to the interpretations in the spirit of understanding their utility and applicability, it is with the recognition that they will always remain complex and “un-flattened,” and they may not ring true for all who read them. It is my hope though, that for most families, they are true of something.

Returning to Play: The Launching Point of Understanding

So important is the concept of play⁵ that I claimed it to be the “the fundamental concept from which all further interpretations arise” (p. 53). In order to truly understand any of the interpretations I offered, one must consider them within the context of what is “at play.” The “at play-ness” of a concept allows us to consider the history, traditions, and prejudices that accompany these concepts, and allows the reader to understand what is happening. For example, I offered the idea, in Chapter 5, *The Island of Misfit Toys*, that the complete and unconditional acceptance of children at camp allows them to understand that they are differently suited to their environment. This idea, on its own, is limited in how it contributes to new understandings. In order to fully appreciate this idea

⁵ Play, in the sense of what is “at play” in children and families at cancer camp.

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

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

Returning to Misfit: Finding Fit

Cancer does not fit well in the regular world. Simply by virtue of receiving that diagnosis, the children and their family members are immediately placed in a situation where they no longer fit. We cannot underestimate the importance of what it means to find fit with something, somewhere. For many children with cancer, the first time they

feel completely accepted is when they come to camp. Counselors and parents reported the changes in the children – what I believe to be the “side effects” of finding fit and acceptance – as increased confidence, improved physical ability, compassion toward others, and improved social skills. In many ways and for many children, camp is an oasis, a place that provides “refuge, relief, or a pleasant contrast” (Merriam-Webster, 2012), from the severity of their disease.

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

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

I demonstrated how, when *mis* is separated from *fit*, the word misfit can be understood differently, as something, or someone, that is “differently suited” to the environment, versus the traditional definition of “a person who is poorly adapted to a

situation or environment” (Merriam-Webster, 2012). It is a reminder to challenge preconceived ideas and dominant discourses, and to remember that there is always another way to understand something, or someone.

Returning to Grief: Living With, Versus Getting Over

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

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

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

It is also important to acknowledge the sanctity of the rituals at camp. From magical moments to luminaries, these rituals recognize the extent to which the mental

and physical are intertwined (Wright, 2008), help families remake their world (Bell, 1992), and come to new ways of knowing their grief. To an outsider, camp might appear fun and haphazard, and while it is indeed fun, everything there is done with intention. The rituals of camp offer comfort to children with cancer and their families experiencing grief, and allow for the weight of their grief to be shared, and understood differently.

Returning to Storytelling: Understanding Differently

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

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

Returning to Community: *Sensus Communis*, “Common” Sense

By bringing families to the same physical location, the community of camp instills connection among these families, creating a *sensus communis*. It is this *sensus*

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

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

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

So What?

You are encouraged, upon occasion, in doctoral studies to have an “elevator pitch” of your research – one or two sentences that capture the essence of your study, that you could tell to a stranger in the span of an elevator ride. This was mine: “I’m looking at understanding the meaning of cancer camps for kids with cancer and their families. In other words, we know camp is (generally) a “good” thing, but why? Of equal

importance, why does it matter?” If there is one takeaway from this research I wish to communicate it is this: Children’s cancer camps need to be considered a necessity, versus a luxury, and should even be thought of as a psychosocial intervention for some children and families. The words “psychosocial intervention” might carry a negative connotation, as if without it the family would be destined for disastrous outcomes. To intervene means to occur, or lie, between two things (Merriam-Webster, 2012), therefore I am suggesting intervention in the sense of “lying between” merely existing and fully living, between suffering and enjoyment, and between feeling isolated and feeling a part of something. I am also not suggesting that families and children should be forced to attend camp, but rather that camp is considered important enough by the healthcare staff that it is promoted, discussed year round, and that every effort is made to send these children and families.

In order for cancer camp to be considered a necessity or a psychosocial intervention, it is important to understand where the current barriers lie. One barrier is in the way camp is funded. Cancer camp is a philanthropic entity, funded by public donations coming from individuals or corporations. Sometimes called “soft money,” this type of funding is not secure; there is no guarantee it will be there next year, and predicting donations is a precarious exercise, largely based on the financial health of the local community. Concurrently, the Government of Alberta (2010) has recognized the increasing pressure on the health system to meet the changing health needs of the population, and has deemed “innovative health service delivery” as a strategic priority for health, prompting Alberta Health Service’s (2009) mission statement to include a patient-focused, quality health system that is accessible and sustainable for all Albertans. Cancer

camp, it could be argued, is an “innovative health service delivery” model – it delivers psychosocial care to these families in a powerful, efficient, and effective way, that is external to the regular healthcare system. If cancer camps were to be considered a necessary part of children’s cancer care, and were to become funded (partially or entirely) by our healthcare system, there would no longer be the continual threat of sustainability of these camps due to a decrease in donations (particularly during times of recessions), and it would fulfill the mandate of the government to provide innovative, cost-effective, healthcare. Similarly, if organizations like Kids Cancer Care did not need to rely on public donations to fund the children’s cancer camps each year, they could broaden the scope of funding opportunities, using money to support other programs related to improving the quality of care of children and families of childhood cancer (for example, more pediatric oncology research).

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

part of the regular treatment for children with cancer, and ensuring easier access to trained professionals.

Concluding Thoughts

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

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

Chapter Ten: Determining Value – The Metrics Upon Which Camp is Measured

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

And ah, I think that's a point that's overlooked a lot when it comes to thinking about why am I donating here, why is that important. And I think in this day and age when everything is rush, rush, rush, dollars and dimes, the idea of mental happiness is just not there anymore. And ah, I think it's far more important than I think a lot of people actually think. (Counselor)

I must be disclosing here, and share three particular areas of my background in order to frame the rest of this section. I used to be the Patient Care Manager of the Pediatric Hematology, Oncology, and Blood and Marrow Transplant Program at the Alberta Children's Hospital. I managed a staff of 140, had an operating budget of 10 million per year, and had responsibilities at the local, provincial, national, and international level. Every month, I would receive 15 to 20 reports on my budget, ranging from how much money was spent on medical supplies to salaries and sick time, and I was responsible for ensuring I was meeting my financial targets. It was not uncommon to be given a mandate stating I needed to trim a certain percentage of my budget in any given reporting period, and it was left to my discretion to figure out how to do that. Alberta Health Services (AHS), my employer, made it very clear that it was always about the money. I am perhaps painting a grim picture in some respects but, in truth, I cannot fault them for this. They are responsible for ensuring the sustainability of healthcare in our province, and the vast majority of their decisions need to be centered on fiscal responsibility. As a consumer of healthcare, I want them to do whatever they need to do to ensure I can access medical care whenever I need to. As an employee of the healthcare system, it made it hard to consider anything other than my bottom line and financial targets. Additionally, when I first started my doctoral studies, I met privately with the

former Chief Nursing Officer to discuss what kinds of roles existed for PhD prepared nurses within AHS. In no uncertain terms, I left knowing that the only research AHS was interested in was that which could provide cost savings. They only valued quantitative research.

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

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

⁶ A performance measure used to evaluate the efficiency of an investment or to compare the efficiency of a number of different investments. To calculate ROI, the benefit (return) of an investment is divided by the cost of the investment; the result is expressed as a percentage or a ratio (Investopedia, 2012).

Obviously, that did not happen (for many reasons) and as I sit here today, I am very thankful it did not. I cannot, however, say that I have reconciled the tension I felt around the *perception* of the value of hermeneutic research in the world where bottom lines, money, and data reign supreme. Many people, I offer, do not “get it,” and I have had many instances where I have realized the value of the hermeneutic research is being lost on them because they are so focused on, “What do you mean there is no method? Why is the sample size so small? You did not use random sampling?” They are always caught up in the fact that there are no numbers, statistics, or data (in the quantitative sense), and I have felt frustrated at their lack of understanding around the value of hermeneutic research. Yet, when I remember the history and traditions from where I have come, I understand their ignorance.

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

Social Return on Investment

A social return on investment (SROI) is a relatively new methodology that uses a principles-based approach that values change that would not otherwise be valued (SROI Network, 2012). It assigns monetary value, by way of financial proxies, to traditionally non-valued, overlooked, or misunderstood things such as the environment, quality of life,

and self-confidence (SROI Canada, 2012). An SROI offers a common language between those who are familiar with the value of projects, like an organization (e.g., AHS), to investors with less information or understanding. It shifts the conversation from cost to value, by measuring the impacts that really matter (SROI Network, 2012).

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

SROI is based on seven principles:

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

appropriate benchmarks, targets and external standards.

- Be transparent: Demonstrate the basis on which the findings may be considered accurate and honest, showing that they will be reported to, and discussed with, stakeholders.
- Verify the result: Ensure appropriate independent verification of the account. (SROI Network, 2012)

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

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

“figure out the ROI of camp,” is understanding what kind of value camp has, and how to best communicate it to the public in a way that is understood. I suggest that in order to truly understand what camp is worth – how to put numbers behind it that appeal to donors and other funding agencies – it is more the social value to which we are referring.

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

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

Trustworthiness and Validity

Qualitative research is evaluated by different criteria of rigor and validity than quantitative research (Koch, 1994). Rigor, in a hermeneutic study, is demonstrated by the believability or trustworthiness of the study (Koch, 1996). Credibility, transferability, and dependability are the constructs upon which trustworthiness (rigor) is established (Guba & Lincoln, 1989).

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

read the study and offer feedback and insight that might not have been otherwise considered, the credibility of this hermeneutic research was enhanced.

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

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

moment, in such a way as to have the reader understand, and thus, be able to find similarity to another situation.

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

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

Luminaries

- *“they put a candle in it but first you have to decorate it and write a memory of your somebody special that has cancer or passed away from cancer and then you make the luminary around it, you glue it on top and then you put it in the water and you say a prayer or make a wish and you put it off into the pond, and it’s dusk at that point and it’s all lit...it’s really beautiful.*
- *Such a great visual...use this somehow? Light, ceremony, symbols (Gadamer), ritual (Gadamer)*

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

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

Validity in interpretive inquiry, according to Lather (1993), is a form of recovery and legitimization which incites discourse. Validity lies in the attempts to resist closed truths of the past encased in the shape of rigid, tight arguments, to recover possibilities, and to free the present for discussion, new thoughts, and practices. First and foremost, validity is an experience of application; it does not arise out of the past but from the future, becoming something only in the way it is lived out. (p. 35)

In addition to the above, validity is demonstrated in hermeneutic research when the study is true to the philosophical paradigm with which it aligns itself, when the interpretations are justifiable and are true of *something*, and when the interpretations are relevant and meaningful, adding to the body of knowledge on the intended topic. “Truth” in interpretation is a meaningful account that corresponds to experience (Davey, 2006). There may not be an absolute answer but there may be better answers that help bring forth understanding.

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

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

In summary. A story must be judged according to whether it *makes sense*. And “making sense” must be here understood in its most direct meaning: to make sense is *to enliven the senses*. A story that makes sense is one that stirs the senses from their slumber, one that opens the eyes and the ears to their real surroundings, tuning the tongue to the actual tastes in the air and sending chills of recognition

along the surface of the skin. To *make sense* is to release the body from the constraints imposed by outworn ways of speaking, and hence to renew and rejuvenate one's felt awareness of the world. It is to make the senses wake up to where they are. (Abram, 1996. p. 265)

It is my hope that this research is valid in the sense that it is telling of something, and that truth lies in the possibility that the interpretations have opened up the topic of children's cancer camps (Madison, 1988). Truth, Jardine (2006) reminded us, is open and always becoming, and the interpretations I have offered are not because I believe them to be true but because I believe them to be the best (Madison, 1988). The work is deemed valid when the reader acknowledges, "ah, yes, this is right," and there is resonance with the topic (Gadamer, 1960/1989).

Limitations, Strengths, and Future Research

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

Limitations. The biggest limitation of this study is that the interpretations may not be understood by, taken up, or resonate with those who read them. This is a limitation not just of my research, but also with all interpretive work. Hermeneutics is

always the answer to a question that could have been answered differently (Gadamer, 1960/1989), and as such, I and other hermeneutic researchers can never escape the fact that our research may not be as impactful as we would have liked.

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

This study was undertaken within a doctoral program in the Faculty of Nursing at the University of Calgary and some might wonder at the fact that the interpretations offered are not nursing specific – in fact, the word “nurse” rarely appears in this dissertation. It is true – this is not a nursing-specific dissertation. However, it is not specific to any discipline – it is specific to children with cancer and their families and how we might understand what kind of meaning children’s cancer camps have for them. The understandings that have come from this research can be utilized by anyone, and just

because I am a nurse does not imply that this is only nursing knowledge. In fact, in the original design of this study, I was intending to interview the camp nurses, not the counselors. It became quickly apparent to me, however, that the counselors were the ones who would be able to give me the kind of information I was seeking by virtue of the amount of time and types of interactions they had with the children and families. I needed to stay true to the research question (versus my discipline) and seek out participants that could best inform the topic.

Strengths. Gadamer (1960/1989) said that “always, already” is the starting point for hermeneutics and that, in hermeneutics, we are stepping into something that already is. That “something that already is,” is part of our lifeworld, and Husserl (cited in Dowling, 2007) reminded us that we already know something about it – we do not generally start from the beginning. I already knew something about children with cancer and their families. I had worked with them in many capacities for 15 years, and my prejudices (in the hermeneutic sense of pre-understandings) were well formed. I believe this to be the greatest strength of this research, because of the fact that, in interpretive work, not only is there is always a relationship between the researcher and the researched, but there is also a relationship to the particular (Smith, 1991). Interpretive work, said Smith (1991), makes you more susceptible to the particular, and because of my background and history that have formed my prejudices in this respect, I was intensely susceptible to the particular, in this research. I believe my prejudices allowed me to see what was going on, and sense what might be happening in a way that someone else, without the same history, could not. It is my hope that this put me in a position to make these interpretations speak loudly enough to be heard and understood by others. This writing is not about me, of

course, but of me (Smith, 1991), and in hermeneutics we can never separate ourselves from understanding.

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

Implications for future research. I was left with several questions after my research that could be considered as future research questions. I questioned how families reconcile the two worlds of camp and the "real world" – one, a place of acceptance, fit, support, and community, and the other often described as the antithesis, at times. I found myself curious what that was like, going back and forth between these different environments, and believe that, by understanding how they accomplish this reconciliation, further support could be offered to these families.

It would also be interesting to understand the meaning of camp for homogenous groups within this community, for example bereaved families or newly diagnosed families. The families I interviewed were mixed, in terms of their placement in the childhood cancer experience, and while this was intentional, it might be interesting to understand more fully the experiences of families who are the most similar to one another.

Chapter Eleven: *Ordo ab Chao* – Order from Chaos

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

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

Cancer camp has reminded me that the more sophisticated the science of childhood cancer becomes, the more obvious it is that curing the disease is only half the battle. While a great deal of attention has been given to cure, more attention is needed in areas of care. As more and more children survive the disease, the pediatric oncology community is still discovering the long-term effects of treatment, and there are as many

psychosocial long-term effects of therapy as there are physical effects. Understanding the meaning of cancer camps for the child and family can help healthcare professionals and organizations like Kids Cancer Care refine and improve upon programs and services offered to these children and families, thereby improving upon the quality of care they receive. It is my hope that research, like this, can also be utilized to further legitimize the camp experience as one of significant benefit to children and families.

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

We are no longer able to approach this like an object of knowledge, grasping, measuring and controlling. Rather than meeting us in our world, it is much more a world into which we ourselves are drawn. [It] possesses its own worldliness and, thus, the center of its own Being so long as it is not placed into the object-

world of producing and marketing. The Being of this thing cannot be accessed by objectively measuring and estimating; rather, the totality of a lived context has entered into and is present in the thing. And we belong to it as well. Our orientation to it is always something like our orientation to an inheritance that this thing belongs to, be it from a stranger's life or from our own. (Gadamer, 1994, p. 192)

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

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Appendix A: Eligibility Requirements

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

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

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

- Be employed as a counselor at Camp Kindle during the July/August 2012 season;
- Be 18 years of age or older;
- Be fluent in English.

Appendix B: Consent Form – Adult (Parent/Guardian)

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

SPONSOR: Not applicable

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

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

BACKGROUND

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

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

WHAT IS THE PURPOSE OF THE STUDY?

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

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

Your participation in this research will involve the following:

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

WHAT ARE THE RISKS?

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

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

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

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

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

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

DO I/WE HAVE TO PARTICIPATE?

You are under no obligation to participate in this study.

Voluntariness and Withdrawal of consent

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

By contacting the principal investigator or doctoral student with your decision to withdraw;

By not attending, or canceling, your interview appointment;

By stopping an interview and advising the researcher/facilitator that you cannot stay, wish to leave and/or withdraw from the study.

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

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

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

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

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

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

WILL MY/OUR RECORDS BE KEPT PRIVATE?

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

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

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

SIGNATURES

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

Dr. Nancy Moules (403) 220-4635

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

 Participant's Name

 Signature and Date

 Investigator/Delegate's Name

 Signature and Date

 Witness' Name

 Signature and Date

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

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

Appendix C: Consent Form – Adult (Counselor)

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

SPONSOR: Not applicable

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

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

BACKGROUND

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

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

WHAT IS THE PURPOSE OF THE STUDY?

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

WHAT WOULD I HAVE TO DO?

Your participation in this research will involve the following:

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

WHAT ARE THE RISKS?

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

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

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

WILL I BENEFIT IF I TAKE PART?

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

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

DO I HAVE TO PARTICIPATE?

You are under no obligation to participate in this study.

Voluntariness and Withdrawal of consent

Your participation in this study is voluntary. You may withdraw from the study at any time without jeopardizing your relationship with the Alberta Children's Hospital, Stollery

Children's Hospital, or the Kids Cancer Care Foundation of Alberta. You may withdraw from the study in a number of ways:

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

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

WHAT ELSE DOES MY PARTICIPATION INVOLVE?

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

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

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

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

WILL MY RECORDS BE KEPT PRIVATE?

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

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

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

SIGNATURES

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

Dr. Nancy Moules (403) 220-4635

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

 Participant's Name

 Signature and Date

 Investigator/Delegate's Name

 Signature and Date

 Witness' Name

 Signature and Date

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

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

Appendix D: Assent

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

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

Why are we offering this study?

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

What will happen during this study?

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

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

Are there good things and bad things about the study?

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

Who will know about what I do during this study?

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

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

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

Assent:

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

Name of person who obtained assent

Signature

Date

Appendix E: Sample Interview Questions

Kids (with cancer and siblings)

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

For parents:

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

For counselors:

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