

## **Delivering Care to Children and Families with Childhood Cancer**

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### **Background**

In response to the stress of the childhood cancer experience, children's cancer camps arose in the 1970s as a way for children and their families to escape the rigidity and severity of cancer treatment (Bluebond-Langner, Perkel, Goertzel, Nelson, & McGeary, 1990). 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 2013, a philosophical hermeneutic study was conducted to understand the meaning of children's cancer camps for the child with cancer and the family. Twenty family members from six families, and a focus group of five camp counselors, were interviewed in order to bring understanding to this topic.

### **Research Says**

Findings from this research revealed that camp means different things for different families, and that much is at play in the cancer camp experience.

1. *Finding acceptance and fit.* From loss of hair due to chemotherapy, to brain tumors, radiation therapy, or unrelated concurrent illnesses or syndromes, most children who have experienced cancer have also experienced looking, or being, different from their healthy peers at some point along the cancer trajectory. Simply by virtue of receiving that diagnosis, the children and their family members are immediately placed in a situation where they no longer fit. 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 – the “side effects” of finding fit and acceptance – as increased confidence, improved physical ability, compassion toward others, and improved social skills. This is significant because peer relationships are an important index of a child's social competence and psychosocial adjustment (Vannattaa, Gartstein, Zeller, & Noll, 2009). Establishing relationships with peers is a major developmental task of preadolescence and adolescence (Sullivan, 1953) and provide an important context for learning social skills and mastering the complexities of cooperation and competition (Hartup, 1999; Rubin, Bukowski, & Parker, 2006). Cancer camp provided an environment of unconditional acceptance, where children and adolescents were able to gain vital skills they need to function in the world as an adult.
2. *Grief as something to live with versus “get over.”* Grief, in childhood cancer, is not only borne by families who have lost a child, but also exists as anticipatory grief brought about by living in constant fear of losing a child. 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, this research suggests that they are given space in which to understand their grief differently. This research highlighted the profound impact of the rituals at camp (e.g., “magical moments,” campfires, recognition of children who have died), and how these may become a part of the grief process. Rituals are intimately linked with emotion, and are thought not only to be a window by which people make, and remake, their worlds (Bell, 1992), but can also be an effective healing catalyst. Through its rituals, cancer camp is a means by which the relationship with grief evolves,

and families are able to incorporate grief into their lives, rather than feel it is something they need to overcome.

3. *Storytelling as a means of re-shaping and understanding traumatic experiences.* Storytelling is said to have been around since the development of language. We come from a tradition of storytelling that served a practical purpose of how to live in the world. Our stories today, though not often practical, remain practical in the sense helping us making sense and increasing understanding of personal experiences. Stories are how we learn and often are told not to say what we know, but to find out what we know. 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, like a diagnosis of cancer, 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.
4. *Solidarity of the community as one that creates intense, healing bonds.* Central to the idea of community, is the concept of belonging to something, and this community of childhood cancer isn't one that people enter willingly, yet once inside, appears to offer a profound sense of belonging. There is a privacy to this community – even those who have worked with these children and families for years can not lay claim to truly understanding. By bringing children and families to the same physical location, the community of camp instills connection among these families, creating a deep sense of community. It is this sense of community, this research concludes, 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.

### **The Value of Camp**

Suggested in this research is the idea of thinking about camp from a value perspective. There is a changing financial climate in much of the world, and cancer camps, like other organizations, are being called upon to articulate their value in a way that donors understand. Determining the value of camp is difficult however, because so much of its value is social in nature, not financial. A proposed way to fill this gap is by using the methodology of social return on investment (SROI). SROI 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). SROI offers a common language between organizations like cancer camps and investors, and shifts the conversation from cost to value by measuring the impacts that really matter (SROI Network, 2012).

### **Bottom Line**

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. Cancer camp, it is concluded, is not “just fun” or “just camp” – it is a way of delivering care to children and families with

childhood cancer. Camp should be considered a necessity, versus a luxury, and should even be thought of as a psychosocial intervention for some children and families. In addition, this research speaks to the need incorporate a tool such as Social Return on Investment, when questions of social value are present.

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