**Okizu: Continuously improving our programs to meet our mission goals and objectives**

Since shortly after its founding in 1982, Okizu has sought to include stakeholders in program planning and evaluation through questionnaires which are sent to campers, parents, and volunteers, as well as a Medical Advisory Board which meets regularly to offer the opportunity for input from the medical professionals who refer their patients and families to our programs. Over the years, our programs and our mission have grown and changed in response to the input we have received from these questionnaires, which we continue to send out after every program session we offer. In the early ‘80s, we saw our mission as to provide a fun camp experience for children suffering from cancer and having to endure the traumatizing treatment that is required. It was meant primarily as respite and recreation for these kids who are unable to participate in so much of what childhood is about. Relatively quickly, we saw the need to provide support to all members of these families, who are impacted in many ways by the cancer experience.

The patients, obviously, are critically ill, and need to spend lots of time in hospitals undergoing frightening and often painful procedures and treatments. They are separated from their peers and from their usual social and developmental learning environments, and this separation impacts their ability to continue to grow and develop in major ways. They feel isolated, alone, different, incompetent, and fearful for their future.

The parents are facing what likely is every parent’s worst nightmare: they are threatened with the loss of a child. Coupled with that threat is the need to completely upend their lifestyle and habits in order to accommodate the needs of their child’s illness. Treatment centers are often far from the home, and children with cancer often spend long time periods confined in the hospital. In two earner families, one parent is often forced to take an extended leave in order to be with the ill child in the hospital. The other parent is then forced to adopt single parent mode in maintaining the household and caring for well siblings. This double whammy means that all aspects of life are stressed in the context of a considerably reduced family income. Parents feel often that they are facing these challenges alone, isolated from their usual routines, forced into uncomfortable and frightening scenarios, and stressed in every aspect of their lives.

The well siblings in the family are in some ways the most impacted from the psychological and emotional perspective. They are well, and therefore their needs suddenly are subordinate to the needs of the illness. They are expected to continue in their “normal” routines, but be always ready for changes in those routines when their ill sibling suddenly needs to be taken to the hospital in the middle of the night, or when both parents need to be away from home for long time periods, or when no parent is available to help them with their homework or take them to soccer practice or answer their questions and calm their fears. Everyone they meet asks them how their ill sibling is doing, or how their parents are doing. But few ever think to ask how they are doing, and they often feel like the world has forgotten that they exist. They feel anger and jealousy, which leads to guilt and low self esteem. They often feel very alone as they face these issues as well, because no one they meet at school or at church or on their sports team is likely to have faced anything even remotely similar. Additionally, they are less likely to receive support from the treating institution in the form of counseling or psychosocial professional intervention, because they may be far from the treatment center and unable to visit regularly.

Recognizing the way all family members are impacted by childhood cancer, we expanded our mission and programs to provide Family weekends (to include the entire family and to focus on the needs of the parents), and then siblings’ camps (to focus on the needs of the well siblings). We also added bereaved Family weekends, a bereaved teen program, and a program for teens and young adults. We quickly realized that the power of community building in a residential camp program is the perfect setting to provide peer support and relieve to some extent the sense of isolation that these families feel. This community also allows children to reconnect with age peers, catch up in socialization skills, learn new skills and thereby feel more competent, gain independence, learn responsibility, and work with others in a team. We restated our mission as to provide peer support, respite, mentoring, and recreational programs to all members of families affected by childhood cancer, and we set out to study in more depth the issues which our client families are facing and to strengthen our programming to more effectively meet those needs.

In 2001 we performed a pre-post camp evaluation study with our sibling campers to look at anxiety, self-esteem, quality of life, and post traumatic stress symptoms, and how they were modified by the camp experience. We found that our sibling campers came to camp with increased anxiety, lowered self esteem, poorer perceived quality of life, and significant post traumatic stress as compared to unaffected children. After the camp experience, these sibling campers had improved in all four of these key areas of function to a significant degree. Several publications have resulted from this study, which appeared in the literature over subsequent years, and are included with our outcomes results (Packman et al 2004, 2005, and 2008).

In 2008, we performed another study using a new instrument designed to look at what aspects of the camp experience were most important to the campers. This study included patients, siblings, and parents. The results of this study also have been published in the peer reviewed literature, and campers reported that the recreation opportunities, peer support, and respite from their lives at home were reasons they appreciated the camp experience. Parents reported that peer support for their children, respite for themselves and their children, and improvements to their child’s behaviors and level of independence were helpful features of the camp experience (Wu et al 2011).

In 2008, 2009, 2010, 2011, and 2013 we used instruments selected from the American Camp Association (ACA) outcomes measurement tools, and explored our campers learning and skill attainment in friendship, teamwork, perceived competence, responsibility, independence, family citizenship, and affinity for exploration. Our campers reported that their skills increased in all of these domains, but particularly in friendship, teamwork, independence, and exploring new skills and experiences. All of our core mission goals (peer support, respite, mentoring, and recreation) contribute to the improvement documented through the ACA measures, and we continue to use these measures intermittently to verify that our programs continue to created opportunities for our campers to learn new skills in these arenas. Summary results from the questionnaires administered in all of these years are included with our outcomes results.

In 2012, we again mounted a more ambitious study using an instrument created for use in special medical needs camps (the Pediatric Camp Outcomes Measure, Simons et al, Children’s Health Care 37:158-169, 2008).This measure explores camper functioning in four domains: physical function, emotional function, social function, and self esteem. This study showed that children, both patients and siblings, who participate in camp programs self report relatively good function in all of these domains in the context of the camp programs. Interestingly, however, the siblings report worse function than the patients in emotional and social functioning, likely reflecting their lack of support in the family and medical treatment arenas. This study also verified that campers (both siblings and patients) from families where the patient was still in active treatment reported worse function in both individual domains and the overall score from the PCOM measure. This data is currently still being analyzed and a manuscript is in preparation. A summary of the key findings is included with our outcomes results.

In 2014 we developed a new questionnaire, to try to dissect further the peer support aspects of the campers’ experience. We questioned the campers about how easy it was to make friends, how easy it was to talk to their friends about their cancer experiences or about their feelings, how well they thought they understood or were understood by their camp friends, and whether spending time with others who shared their experience with cancer (either personally or in their family) was helpful. We also asked for feedback about specific camp activities which are designed to help make these peer connections, like the unit campfire the first night of camp to connect with new and old friends, and the Inspiration ceremony toward the end of the week when campers talk to the entire camp community about what Camp Okizu has meant to them. The majority of campers feel that making friends at Okizu is easy, that they understand and are understood by their camp friends better than friends at home, that they are able to talk about their experiences and their feelings to their camp friends, and that spending time with others who share their cancer experience is helpful. A summary of the data from the 2014 questionnaires is also included with the outcomes results.

As we learn more about how having cancer in a child affects family members, we will be able to continue to modify and augment our programming to make it more effective in providing peer support, respite, mentoring, and recreational programs to our client families. We plan to continue to gather data every year to better our understanding of the impact that cancer is having on our client families, and to assess the effectiveness of our programming in helping them to cope. Future plans will include a more specific assessment of our teen and young adult programming, bereavement programming, and the impact that participating in Okizu programs has on our hundreds of mostly young volunteers each year. One measure that we do have about the volunteers is that nearly half of them are now graduates of our camp programs who vote with their feet by coming to camp as volunteer staff to help make the experience which benefitted them available to campers who are following in their footsteps.

The other information which we collect is free-form comments from children and families about their perception of the value of their camp experience. Many of our young campers and their parents over the years have described participation in Okizu programs as transformational and life-changing. A complete list of the comments that campers left at the end of the questionnaire in 2011 is included at the end of the PowerPoint presentation that is included in our outcomes results. A parent at a Family camp from the fall of 2014 expressed it very well: “We go to the hospital to get rid of the cancer, but we come to Okizu to heal.” When these children and their parents have the opportunity to heal from the psychological, emotional, and physical trauma which they endure at the hands of Cancer, then they are able to move past those experiences and continue to lead productive lives, contributing to our society rather than becoming dependent on society for their care and support. That is the ultimate measure of the success of our programs.