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Benefits of disease-specific summer camps: Results from quantitative and qualitative studies at Roundup River Ranch

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ABSTRACT

Background: The purpose of this study is to examine the benefits of disease-specific summer camps (DSSC) for children with chronic and/or life-threatening illnesses.
Methods: Participants were children (11–17 years) attending DSSC during summer 2015. The quantitative study evaluated positive affect, meaning/purpose, and peer relationships at three time points (before camp, one week after camp, and three months after camp). Linear mixed models assessed changes in outcomes before and after camp for new and returning campers. The qualitative study involved semi-structured interviews with questions about camper mood, goals, and peer interactions, both at camp and at home. A two-phase thematic analysis was utilized with operational definitions of themes derived from Social Comparison Theory and Psychosocial Development Theory.
Results: Campers reported more positive affect, greater meaning and purpose, and improvement in quality of peer relationships one week after camp; however, changes were not maintained three months after camp. The most common benefit of DSSC identified in the interviews was self-efficacy, followed by emotional support and positive mood. Social comparisons were made by 74% of campers. Acceptance (i.e., by peers, of self, of illness) was the most common benefit maintained after camp.
Conclusions: Study results provide greater insight into the social, emotional, and developmental benefits of attending DSSC, and highlight avenues for future intervention or program development (e.g., community-based camp events, school/peer education programs). Further, results can be used to assist camp directors and planners with age and disease-specific programming as well as support fundraising efforts for DSSC.

1. Introduction

Advances in medical care over the past 25 years have improved life-expectancy and quality of life for children with chronic and/or life-threatening illnesses. As children with chronic illness advance through primary and secondary school, they are faced with increased academic and psychosocial challenges. For example, school absenteeism associated with chronic illness contributes to reduced peer interaction, impacting quality of friendships, self-esteem, and feelings of isolation (Shiu, 2001). In addition to this disruption in typical childhood development, activities enjoyed by healthy children, such as overnight summer camp, may be limited due to required medical care and other potential accommodations (e.g., wheelchair accessible, modified diet for food allergy).

Summer camps have been shown to provide many benefits for childhood development, including positive identity, social interactions, and skill development (Thurber, Scanlin, Scheuler, & Henderson, 2007). Disease specific summer camps (DSSC) allow children with chronic and/or life-threatening illnesses to "just be kids" in a medically-safe environment, which in turn provides camping experiences similar to healthy children. A growing body of literature has also shown that DSSC provide psychological and social benefits for campers, including better self-esteem, increased disease knowledge, improved disease management, less anxiety, and greater social functioning (Epstein, Stinson, & Stevens, 2005; Moola, Faulkner, White, & Kirsh, 2014).

In addition to campers simply having fun, different mechanisms have been considered that may contribute to the previously identified positive outcomes. For example, DSSC allow children to compare

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themselves with other children who also have chronic illnesses, which can normalize the child's illness experience, and provide a form of social support they may not otherwise be able to access (Meltzer & Rourke, 2005; Wu, Geldhof, Roberts, Parikshak, & Amylon, 2013). Because DSSC provide campers a medically-safe environment with supportive peers outside of home, school, or the hospital, youth have the opportunity to be challenged and participate in new activities. Thus DSSC promote a greater sense of control and accomplishment, which can result in more positive self-perceptions, which can contribute to both improvements in self-esteem, as well as increased medical adherence (Odar, Canter, & Roberts, 2013). Despite these given benefits, the ability to make robust conclusions about long-term effects of DSSC is lacking. Several studies have confirmed physical and psychological benefits after one week at DSSC; however, maintenance of improvements may not last > 4–6 weeks (Epstein et al., 2005; Kiernan, Gormley, & Maclachlan, 2004; Moola et al., 2014).

While the number of studies examining the psychosocial benefits of DSSC has grown over the past 10 years, only a limited number of factors that contribute to well-being and health-related quality of life have been considered (Moola et al., 2014). Thus, additional work is needed to consider novel areas of well-being and health-related quality of life (HRQOL), including positive affect (i.e., positive or rewarding affective experiences, including pleasure, joy, elation, engagement, and excitement) and meaning and purpose (i.e., hopefulness, optimism, and goal-directedness). In particular, hopefulness is a determinant of psychosocial adaptation and is recognized as an influential component in an individual's ability to respond to illness (Ritchie, 2001). Higher levels of hope among children with chronic illness are associated with more positive coping strategies throughout the course of illness (Woods, Mayes, Bartley, Fedele, & Ryan, 2013).

Although quantitative research approaches are valuable in the outcome data they provide, validated questionnaires may tap constructs that are important to camp planners and researchers, but not necessarily to campers themselves. As such, there is value in allowing campers to provide feedback about their experiences using a qualitative approach. Semi-structured interviews with campers can help capture campers' perspectives on why camp is meaningful, as well as identify mechanisms that help explain why campers benefit from DSSC. That is, common underlying themes can be identified as campers communicate developmental and psychosocial areas affected by camp that may not otherwise be addressed through standardized questionnaires. Incorporating campers' perspectives on the benefits of camp may help inform how DSSC can be organized to increase the likelihood of lasting improvements on positive self-perceptions, peer relationships, and medication adherence. The combination of quantitative and qualitative outcome data can provide richer, more detailed information that can be used in planning age and disease-specific programming, both during and after camp.

The purpose of this study was to examine the benefits of DSSC for children with chronic and/or life-threatening illnesses through both quantitative and qualitative studies. The use of different study designs capture quantitative changes to camper well-being and HRQOL during and after camp, while highlighting common themes among campers' thoughts and experiences at camp, as well as how camp impacts their lives during the rest of the year. We expected that after attending a week of DSSC, campers would report improvements in positive affect, meaning and purpose in life, and peer relationships one week after camp ended; however, based on previous reviews that document a lack of long-term benefits (Epstein et al., 2005; Moola et al., 2014), we expected that these benefits would not be maintained three months after camp. Theoretically supported themes from semi-structured interviews were explored with no specific hypotheses.

2. Camp setting

Roundup River Ranch provides camp experiences to children with serious illnesses and their families in Gypsum, Colorado. Both week long summer camps and family weekends throughout the year are offered at no charge to campers and their families. Both summer and family camp sessions are organized to bring together campers with similar diagnoses or illness experiences. Camp activities include a climbing wall, zip line, ropes course, canoeing, fishing, archery, arts and crafts, singing, dancing, stage night, and field games.

The camp uses an “intentional programming philosophy” that challenges campers by choice, allowing them the ability to “discover new talents, hidden courage, and exhilarating successes” (www.roundupriverranch.org). No illness specific programming is included as part of the camp sessions. Full time summer staff at Roundup River Ranch receive intensive two-week training on providing physical and emotional support to camper within a fun and safe environment. Staff also participate in training on the different medical and psychosocial aspects of each illness group, as well as training in building communication skills and managing camper behavior.

3. Quantitative study

3.1. Study design

A longitudinal research design was used to quantitatively measure changes in subjective well-being at three time points: before attending camp (T1), one week after camp ended (T2), and three months after camp ended (T3). The study was approved by the Institutional Review Board at National Jewish Health.

3.2. Participants and procedure

Sixty-one children with chronic illness who were scheduled to attend Roundup River Ranch in the summer of 2015 provided informed consent/assent; however 19 did not complete any of the three surveys. An additional 6 were excluded from analyses as they either completed only T1 ($n = 3$) or T1 and T3 ($n = 3$) surveys. The current analyses were performed using data from 36 campers who had at least T1 and T2 data. There were no significant differences in age, sex, race, or ethnicity between campers who completed at least T1 and T2 surveys and those who were excluded due to incomplete data.

Of the remaining 36 campers who completed both T1 and T2, 24 completed surveys at all three time points. There were no significant differences between participants who completed two or three surveys with regard to age, sex, race, ethnicity, or for any of the three outcome variables at T1. However, while 82% of new campers completed all three surveys, only 53% of returning campers completed all three surveys, $\times^{2}(1) = 3.57$, $p = .06$. Data were not collected on why participants did not complete the third survey.

The 36 campers who completed at least two assessments were ages 11 to 17 years ($M = 13.3$, $SD = 1.8$); 61.1% female; 80.6% Caucasian, 5.6% African American, 13.9% multi-racial; with 11.1% reporting Hispanic ethnicity. Campers attended one of three DSSC sessions (with each session including children with different chronic illnesses): *Session A* - children with cancer/tumors ($n = 10$) or sickle cell disease ($n = 2$); *Session B* - kidney disease/kidney transplant ($n = 8$); or *Session C* - Crohn's disease or colitis ($n = 2$), celiac disease ($n = 9$), or liver disease/liver transplant ($n = 5$).

Campers were sent an invitation to participate in the study by postal mail or email, depending on the family's preference for communication from camp. Within a week of sending the letter, a member of the study team contacted the family by telephone to answer any questions about the study, obtain a verbal consent from the parent, and obtain an email address where a link to the online survey was sent. To ensure all campers could participate, even if the family did not have regular internet access, there was an option for paper copies of the questionnaires to be sent with a self-addressed stamped envelope; however, all participants completed the surveys online. The camp medical and program