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A multisite evaluation of summer camps for children with cancer and their siblings

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Abstract

Summer camps for pediatric cancer patients and their families are ubiquitous. However, there is relatively little research, particularly studies including more than one camp, documenting outcomes associated with children's participation in summer camp. The current cross-sectional study used a standardized measure to examine the role of demographic, illness, and camp factors in predicting children's oncology camp-related outcomes. In total, 2,114 children at 19 camps participated. Campers were asked to complete the pediatric camp outcome measure, which assesses camp-specific self-esteem, emotional, physical, and social functioning. Campers reported high levels of emotional, physical, social, and self-esteem functioning. There were differences in functioning based on demographic and illness characteristics, including gender, whether campers/siblings were on or off active cancer treatment, age, and number of prior years attending camp. Results indicated that summer camps can be beneficial for pediatric oncology patients and their siblings, regardless of demographic factors (e.g., gender, treatment status) and camp factors (e.g., whether camp sessions included patients only, siblings only, or both). Future work could advance the oncology summer camp literature by examining other outcomes linked to summer camp attendance, using longitudinal designs, and including comparison groups.

Keywords

camp; evaluation; pediatric oncology; psychosocial; therapeutic recreation; support program

Introduction

Summer camps for pediatric cancer patients and their families are common. For example, in the United States and Canada, there are over 65 Children's Oncology Camping Association

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International (COCA-I) camps, many of these focusing on not just oncology patients but also their siblings and other family members (Children's Oncology Camping Association International, 2014). Some camps hold sessions specifically for oncology patients or for siblings, and other camps convene sessions that both patients and siblings can attend concurrently. Summer camps for children with cancer and their families have a variety of goals. For instance, oncology summer camps typically aim to provide campers with a community of peers who have had similar experiences with cancer. In the context of such a community, campers may experience improvements in their self-efficacy, self-esteem, and independence. Camps also offer children and families respite from their cancer experience through recreation opportunities (e.g., outdoor activities, music and drama, arts and crafts) (Martiniuk, Silva, Amylon, & Barr, 2014). Together, the combination of social support through a camp community and camp activities is thought to positively impact campers' physical, psychological, and social functioning (Martiniuk et al., 2014).

Despite the large number of summer camps for children with cancer and their families, there is a relatively small literature documenting outcomes associated with children's participation in summer camps. Findings in the existing literature indicate that children who attend particular oncology camps report positive impacts of the camping experience on a range of outcomes related to emotional, physical, self-esteem, and social functioning. As an example, oncology camp participation has been linked with improvements in children's mood and decreased anxiety (Dawson, Knapp, & Farmer, 2012; Martiniuk et al., 2014; Meltzer & Johnson, 2004). Oncology camps provide opportunities for children to be physically active and to develop their sense of autonomy and competence (Gillard & Watts, 2013). Other findings have highlighted the benefits of summer camp experiences on children's self-esteem and social functioning. These include improvements in self-concept, greater satisfaction with their appearance, and perceiving greater acceptance from peers (Dawson et al., 2012; Martiniuk et al., 2013).

Although this initial literature supports the notion that summer camps contribute to improved functioning and coping among children affected by cancer, the vast majority of studies have focused on single oncology camps. For example, to our knowledge, only one study examined camper outcomes across more than one camp (Martiniuk et al., 2013). However, there have been calls in the literature to conduct multisite oncology camp outcome studies that include larger sample sizes and allow examinations of predictors for differing outcomes between campers (Martiniuk et al., 2014). In addition, the existing literature has not been able to use standardized measures of camp outcomes that would facilitate multisite studies and comparisons of oncology camps. Thus, the aims of the current study were to: (1) use a standardized measure to document camp outcome data across multiple sites and (2) investigate potential differences in camp outcomes by demographic, illness, and camp characteristics.

Data and methods

Sample and data collection

Participants in the current study were children attending summer camps for children with cancer and/or siblings of children with cancer. This was a multicamp study enrolling

children from 19 camps in the United States and Canada. Data were collected during the summer of 2012. Camps held sessions that were 6 or 7 days in length. The study measure was made available to all COCA-I camps for use in quality assurance and quality improvement projects. Individual camps then opted to provide de-identified questionnaire results to a central location for analysis.

All children (cancer patients, survivors, and siblings) attending one of these camps during the summer of data collection were eligible to participate in the study if they were between the ages of 6 and 18 years. Prior to camp sessions, parents were provided a letter describing the purpose and procedures for the research study. Parents could opt out of having their children participate. During the last 1–2 days of camp sessions, children were provided a quiet space to complete the study measures. Children with cognitive limitations or who were unable to complete the questionnaire independently completed the pediatric camp outcome measure (PCOM) with the assistance of a camp staff member who was instructed to read, to explain the questions and the options for answering without introducing their own bias, and then to record the answer which the child gave or confirm that the child had marked the answer appropriately. All study procedures were approved by the Institutional Review Board at the last author's institution.

In total, 2,725 children completed at least some portion of the study measures. 118 of these questionnaires were not evaluable because the respondent (1) did not clearly indicate if he/she was a patient or sibling, (2) was older than 18 years of age, (3) was a staff member and not a camper, (4) was a child of the camp staff and not a cancer patient or sibling, (5) provided the same answer to all questions on the survey, indicating potentially inaccurate reporting. Children who attended camp because they were the son or daughter of adult cancer patients were excluded from the sample ($n = 6$). In addition, all children from one camp were excluded ($n = 317$) due to a copying error, whereby the majority of children received only half of the camp outcome measure. Of the remaining 2,284 children, 2,114 provided complete data on the PCOM. Sensitivity analyses revealed that the mean scores on this measure did not significantly differ when participants providing partial data were excluded. Thus, to simplify presentation of the results, only data from those who provided complete data are included in the current report.

Measures

Demographics—Demographic information about participants was obtained through self-report. This included information on age, gender, and whether the participant had cancer or was a sibling of a child who had cancer. Information was also obtained regarding whether the child with cancer was on-treatment or off-treatment and whether the child had experienced a relapse. Information from siblings regarding whether they were bereaved was collected based on self-report. Data on whether campers were attending camp for their first year, and for returning campers, how many years they had previously attended camp was gathered. Campers also reported on whether the camp session they were attending included patients only, siblings only, patients and siblings together, or was a family camp where parents or caregivers attended along with children.

Pediatric camp outcome measure—The PCOM is a 29-item measure assessing children's perceptions of their camp experience (Simons, Gilleland, McDanel, Blount, & Campbell, 2008). Items are rated on a 5-point Likert-type scale from 1 (negative experience) to 5 (positive experience). The scale produces four subscales that assess children's camp-specific emotional functioning, social functioning, physical functioning, and self-esteem. An overall total score is also calculated. Higher subscale and total scores represent better camp-related functioning. Three items assessing camp satisfaction are not included in the subscale or total scores. The first item assesses how much children liked camp on a 5-point Likert-type scale ranging from 1 = "I hated camp" to 5 = "I really liked camp." The second item uses a 5-point Likert-type scale to assess what campers would tell other children about camp (ranging from 1 = "It was very bad" to 5 = "It was very good.") The last item assesses whether children would want to return to camp the following year (yes versus no).

The scale has demonstrated adequate reliability in prior samples (subscale Cronbach's alphas ranged from 0.80 to 0.89; total score Cronbach's alpha = 0.93) (Simons et al., 2008) and has demonstrated construct validity (Wu et al., 2015). Reliability of the subscale and total scores in the current sample were as follows: 0.75 (emotional), 0.85 (social), 0.64 (physical), 0.74 (self-esteem), and 0.90 (Total).

Analysis—Descriptive statistics (i.e., mean, standard deviation, frequency) were calculated to summarize participant's demographic information. Potential demographic differences between patient and sibling campers were assessed using χ^2 analyses and *t*-tests. The mean and standard deviation of PCOM subscale and total scores were calculated after reverse coding of relevant items. The mean and standard deviation of three questions that do not contribute to the PCOM subscale or total scores were calculated. These questions assess how much campers report liking camp, to what extent they would tell other children that their camp is good, and whether they would come back to camp next year. Next, we used *t*-tests and analysis of variance for subgroup analyses examining whether PCOM scores differed by children's demographic characteristics (i.e., oncology versus sibling camper, first-year camper versus returning camper, gender, on active cancer treatment versus off-treatment) and camp session model (i.e., oncology campers only, siblings only, oncology, and siblings together). Children attending family camps were excluded from the latter analysis because of limited sample size ($n = 20$). Because of the entire sample's relatively large size, which makes it more likely that small differences between groups are statistically significant, we further examined statistically significant findings by calculating effect size estimates (Cohen's *d*) and 95% confidence intervals. Using existing convention, a Cohen's *d* of 0.20 indicates a small effect size, 0.50 indicates a medium effect size, and 0.80 indicates a large effect size (Cohen, 1988). We also used correlations to examine the relationship between children's age and number of years at camp with PCOM subscale and total scores. An adjusted significance level of $p < 0.01$ was used to determine statistical significance due to the multiple comparisons.

Results

Children ranged in age from 6 to 18 years. Participant demographic characteristics are summarized in Table 1. Across 18 camps included in the current analysis, an average of 126

children completed the study questionnaire at each camp (SD = 133, range 22–577). Descriptive statistics for the PCOM subscale and total scores are shown in Table 2. Descriptive statistics for the three PCOM items assessing satisfaction with camp are included in Table 3.

On comparing patient and sibling campers on the PCOM subscale and total scores, the only significant differences were on the emotional functioning [$t(2112) = -4.42$, $p < 0.001$] and self-esteem subscales [$t(2112) = -3.26$, $p = 0.001$] such that patients had higher scores on these domains. The effect sizes for emotional functioning and self-esteem were small (Cohen's d [95% CI] = 0.20 [0.11, 0.28], 0.14 [0.06, 0.23], respectively). Thus, in subsequent analyses, patient campers and siblings were analyzed as a group.

Male campers had significantly higher scores than female campers on emotional [$t(2107) = -3.497$, $p < 0.001$] and physical [$t(2107) = -3.914$, $p < 0.001$] subscales; however, these differences represented small effect sizes (Cohen's d [95% CI] = 0.15 [0.07, 0.24], 0.17 [0.09, 0.26], respectively). Age was significantly and positively correlated with PCOM subscale and total scores such that older age was related to higher scores on self-esteem ($r = 0.43$, $p < 0.001$), social functioning ($r = 0.18$, $p < 0.001$), emotional functioning ($r = 0.15$, $p < 0.001$), and the total score ($r = 0.17$, $p < 0.001$). Campers who were attending camp for their first year had significantly lower PCOM scores on all scales [emotional: $t(708.0) = 6.41$, $p < 0.001$, social: $t(689.3) = 3.96$, $p < 0.001$, physical: $t(704.3) = 3.6$, $p < 0.001$, self-esteem: $t(686.1) = 4.35$, $p < 0.001$, total: $t(693.8) = 5.73$, $p < 0.001$] compared with campers who had attended camp in prior years; however, these effect sizes were small (Cohen's d [95% CI] = −0.35 [−0.46, −0.25], −0.22 [−0.33, −0.12], −0.20 [−0.30, −0.10], −0.25 [−0.35, −0.14], −0.32 [−0.42, −0.22], respectively). For returning campers, number of prior years attending camp was positively correlated with all PCOM subscale and total scores (r_s from 0.11 to 0.18, all $p_s < 0.001$).

Campers reporting that they or their siblings were on- versus off-cancer treatment differed significantly on all PCOM subscale and total scores, such that those who were on-treatment had lower scores [emotional: $t(554.1) = 4.63$, $p < 0.001$, social: $t(559.0) = 4.22$, $p < 0.001$, physical: $t(2041) = 2.75$, $p = 0.006$, self-esteem: $t(542.3) = 4.8$, $p < 0.001$, total: $t(558.9) = 5.13$, $p < 0.001$]. These significant differences were small effect sizes (Cohen's d [95% CI] = −0.28 [−0.39, −0.17], −0.25 [−0.36, −0.15], −0.15 [−0.26, −0.04], −0.30 [−0.41, −0.19], −0.31 [−0.42, 0.20], respectively). There were no significant differences on PCOM subscale or total scores between siblings who reported being bereaved versus those were not, nor between campers reporting they or their sibling relapsed versus not.

There were also no significant differences in PCOM subscale and total scores between camp sessions including only patients, only siblings, or patients and siblings together. Among siblings, those attending camps that included both patients and siblings had significantly higher emotional [$t(867) = -5.02$, $p < 0.001$], self-esteem [$t(867) = -4.24$, $p < 0.001$], and total [$t(871) = -4.15$, $p < 0.001$] scores; however, all were small effect sizes (Cohen's d from 0.16 to 0.34). Among patients, there were no significant differences on the PCOM scores between patients who reported a sibling attended camp with them versus patients who did not have a sibling attend camp.

Summary and discussion

The current study is one of the first to use a standardized measure to assess outcomes across multiple camps serving children with cancer and their families. Campers, on average, reported relatively high levels of functioning across domains assessed by the PCOM, consistent with levels of functioning documented among campers at another chronic illness camp (Simons et al., 2008). High levels of functioning were observed in areas that are expected to be impacted by children's camp participation. Specifically, campers reported high levels on the social and self-esteem subscales. This is consistent with the notion that chronic illness summer camps provide children with unique opportunities to socialize with peers who have similar health experiences and that summer camps provide children with experiences that build self-esteem (Brown, 2005; Martiniuk et al., 2014). Prior studies have demonstrated that children attending oncology camps report high levels of social support and that self-esteem improves pre to postcamp (Conrad & Altmaier, 2009; Packman et al., 2004).

Our results indicated that there were statistically significant differences on the PCOM scores between oncology and sibling campers, male and female campers, and first-year and returning campers. Similarly, there were statistically significant differences between those on- versus off-treatment and siblings who were bereaved versus not. All of the statistically significant differences were small in terms of their effect size. Taken together, these results suggest that the camp experience can be equally helpful to children affected by cancer (i.e., both patients with cancer and their siblings), regardless of their gender, how many years they have attended camp, and treatment and bereavement status. We also found that children's perceptions of their camp experience across domains did not differ based on the type of camp they attended (i.e., camp model of patients only, siblings only, or both patients and siblings). This finding indicates that a diversity of camp models can be effective in supporting children affected by cancer. If multiple camp models are available, it may be important for families to work with medical teams to determine, for each child, what type of camp may be most beneficial. For example, some children are more comfortable attending camp for the first time if a sibling accompanies them, whereas some siblings may benefit from attending camp sessions devoted just to them. Future research could investigate the advantages and challenges, both for families and for camps, associated with implementing each camp model.

Our results vary from prior studies using the PCOM with children attending chronic illness camps. Specifically, the results of one study which included children who had complex heart defects attending a medical summer camp found no significant differences in PCOM scores based on children's demographic characteristics including gender, age, and whether campers were new or returning campers (Simons et al., 2008). Other studies have documented differences in oncology camper's outcomes based on gender and whether campers were patients versus siblings (Conrad & Altmaier, 2009; Sidhu, Passmore, & Baker, 2006).

The current study has several strengths worth noting. This was one of the first studies involving oncology camps across the United States and Canada, allowing a more comprehensive, multisite examination of children's perceptions of their camp experiences.

The current study also used a standardized measure of camp outcomes, the PCOM, which provides a method for assessing outcomes across camps. And finally, because of the large sample size included in the current study, we were able to examine potential demographic, illness, and camp characteristics which could impact camper outcomes.

The findings should also be interpreted in the context of several limitations. Like many prior oncology camp studies, we did not include a control group of children who did not attend summer camp. We used a cross-sectional study design and thus were unable to examine changes in children's camp-related functioning over time. Also, although relatively small in number, we excluded some respondents due to missing data and copying errors that occurred in one camp. The physical functioning subscale demonstrated low reliability in our study, and thus its findings should be interpreted with caution. Our study also did not collect additional medical information, such as type of cancer diagnosis or number of years since diagnosis. Although we combined children with cancer and siblings together for analysis, future studies should also consider the unique needs of patients and siblings (Wellisch, Crater, Wiley, Belin, & Weinstein, 2006).

Future research focused on pediatric oncology camps could use a combination of a standardized measure such as the PCOM with measures that may be tailored to assess outcomes associated with specific camp goals (e.g., measures of children's increased knowledge about cancer). To accommodate the needs of the multiple camps participating in the current study, we were unable to include a control group of children who did not attend camp or to administer pre and postmeasures to campers. It will be important to find ways of including control groups into future camp studies to more robustly demonstrate the benefits of camp attendance. Because it is likely impractical to ask control group children to refrain from attending camp, a waitlist control design or use of a different comparison group (e.g., campers who are not chronically ill) may be more acceptable. Inclusion of a control group will also help examine or rule out other factors that could influence children's camp functioning, such as potential selection bias whereby children with better functioning are more likely to attend camp. Multisite studies could also consider using multilevel modeling approaches to data analysis, which would allow one to account for the possibility that camp outcomes are likely more similar within camps and to account for this when examining predictors of differential camp outcomes. Future studies should also consider prospectively and longitudinally following children to document changes over time, such as precamp, postcamp, and at longer term follow-up (Bluebond-Langner et al., 1990; Packman et al., 2005). To continue building an empirically based literature that supports continued efforts to convene summer camps for children affected by cancer, future studies could assess the degree to which camp participation leads to other positive outcomes, such as decreased use of health-care services or reduced need for behavioral health services. In addition, studies could examine differences in outcomes across medical variables (e.g., cancer diagnosis, years since diagnosis) and other demographic characteristics (e.g., race/ethnicity, socioeconomic status, cultural background), identify demographic and child predictors of camp outcomes, and validate PCOM cutoff scores or ranges of scores that indicate differing levels of functioning.

In summary, children attending oncology camps appear to derive benefits from their camp participation across multiple domains of functioning. Clinicians who work with pediatric cancer patients and their families could explain the range of benefits that may be associated with camp attendance (e.g., benefits to social functioning and self-esteem). Families may also appreciate hearing that attendance at an oncology summer camp has the potential to benefit a range of children, regardless of factors such as bereavement status (for siblings) or disease relapse status of the oncology patient. Although effects were small, the results of the current study suggest that repeat attendance at oncology summer camps may be related to better camp-specific outcomes. Thus, children could benefit from ongoing participation in summer camps. Oncology camps with different models (e.g., patients only, siblings only, patients and siblings attending concurrently) appear to yield similar camp-specific outcomes among children. Siblings may experience some added benefit to attending camps that hold sessions serving patients and siblings concurrently. Future efforts to understand the specific camp processes or activities that lead to positive outcomes are needed. By building the evidence base for the effectiveness of chronic illness summer camps, we will be able to make more informed choices about how to continually improve camps, so they best meet children's and families' needs.

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Table 1

Participant demographic information (patients, siblings, and comparison between groups).

		Patient campers (*n* = 1,230) *n* (%)	**Sibling campers (*n* = 884) *n* (%)**	χ^2	*p*
Gender	Male	581 (47.4)	488 (55.3)	1.5	0.23
	Female	645 (52.6)	395 (44.7)		
Cancer treatment[a]	On-treatment	202 (16.9)	197 (23.2)	12.3	<0.001
	Not on-treatment	991 (83.1)	653 (76.8)		
Cancer relapse[a]	Cancer relapsed	123 (10.9)	143 (18.1)	19.9	<0.001
	Cancer did not relapse	1,003 (89.1)	648 (81.9)		
Camp experience	First-year attending camp	254 (20.9)	216 (24.8)	4.3	0.04
	Returning camper	963 (79.1)	659 (75.3)		
Camp model	Oncology patients only	789 (64.1)	n/a	Not compared due to different applicable models	
	Siblings only	n/a	476 (53.8)		
	Oncology patients and siblings	432 (35.1)	397 (44.9)		
	Family camp	9 (0.7)	11 (1.2)		
Camper's sibling also attended camp[b]	Yes	278 (22.8)	604 (69.2)	449.8	<0.001
	No	941 (77.2)	269 (30.8)		
Bereaved sibling		n/a	125 (14.7)	n/a	
		Mean (SD)	Mean (SD)	*t*	*p*
Age (years)		12.9 (3.1)	12.0 (2.8)	−7.1	<0.001
Number of years camp attended		3.3 (2.9)	2.9 (2.7)	−3.3	<0.001

[a] Siblings were asked to report on their brother/sister with cancer's current treatment and relapse status.

[b] Sibling attended camp at the same time as the respondent.

Table 2

PCOM subscale and total scores (means, standard deviations, range, and comparison between groups).

	Patient campers		Sibling campers		All campers		Possible range	Patients versus siblings	
	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range		*t*	*p*
Emotional	30.2 (4.4)	9–35	29.4 (4.5)	11–35	29.9 (4.5)	9–35	8–40	−4.4	<0.001
Social	39.9 (5.3)	13–45	39.9 (5.0)	14–45	39.9 (5.2)	13–45	9–45	−0.1	0.914
Physical	20.5 (3.2)	6–25	20.8 (3.0)	8–25	20.6 (3.1)	6–25	5–35	2.6	0.008
Self-esteem	22.5 (2.6)	5–25	22.1 (2.9)	7–25	22.3 (2.7)	5–25	5–25	−3.3	0.001
Total score	113.1 (12.6)	55–130	112.2 (12.6)	52–130	112.7 (12.6)	52–130	29–145	−1.7	0.097

PCOM, pediatric camp outcome measure.

Table 3

Camper reported satisfaction with camp (means, standard deviation, frequencies, and comparison between groups).

	Patient campers	Sibling campers	All campers	Patients versus siblings	
	Mean (SD)	**Mean (SD)**	**Mean (SD)**	***t***	***p***
How much did you like or dislike camp?[a]	4.8 (0.5)	4.8 (0.6)	4.8 (0.6)	−1.4	0.17
What would you tell other kids about camp?[b]	4.8 (0.5)	4.8 (0.5)	4.8 (0.5)	−1.6	0.10
	n (%)	*n* (%)	*n* (%)	χ^2	*p*
Yes, I would like to come back to camp next year[c]	1,194 (97.1)	865 (97.9)	2,091 (98.5)	0.76	0.39

[a] Rated on a 5-point Likert-type scale ranging from 1 = “I hated camp” to 5 = “I really liked camp.”

[b] Rated on a 5-point Likert-type scale ranging from 1 = “It was very bad” to 5 = “It was very good.”

[c] Percentages are based on the number of children who responded to the question.