

Program Evaluation of a Pediatric Oncology Camp For Patients and Siblings

Approximately 12,400 children and adolescents in the United States are diagnosed with cancer each year.¹ As a result of recent medical advances, death rates for childhood cancer have decreased significantly in the past several decades. However, the importance of addressing challenges faced by children with cancer, such as social impairment or elevated levels of distress still remain critical.² Childhood cancer greatly affects the family members of the child who is diagnosed. For example, siblings of chronically ill children are at an increased risk for developing mental health problems such as anxiety or depression.³

In addition to other psychosocial interventions, one response to the number of children and adolescents affected by chronic illness has been to develop therapeutic recreation camps. The goals of such camps vary from increasing disease-related knowledge to improving self-esteem; however, the majority embrace the basic mission of meeting the medical needs of campers and improving their psychosocial functioning while providing them

with a fun, normalizing summer camp experience.⁴ It is generally accepted anecdotally that therapeutic camps meet stated goals or are beneficial to campers' overall well-being.⁵ Despite the perception that camps for chronically ill children and adolescents are an effective intervention, scientific investigation regarding the effectiveness and outcomes of these camps is needed.⁶ One way of performing such an investigation is by conducting a program evaluation.

A program evaluation examines the overall effectiveness of a program by examining the way services are delivered and measuring how successful the program is in meeting desired outcomes.⁷ Program evaluations differ in design depending on the purpose of the evaluation. For example, evaluations designed to determine whether a program meets a specific goal, such as successfully increasing disease-related knowledge, are different from evaluations which aim to determine consumer satisfaction with camp experience.⁸ Apart from design, as outlined by Roberts and Steele, several

fundamental components of program evaluation include the collection of demographic information and relevant history such as a child's medical history and prognosis. The inclusion of this information can assist in identification of individual differences among program participants which may influence outcomes. Once a program has been evaluated, the knowledge acquired has the potential to benefit other similar programs, inform consumers of effectiveness and outcomes, elucidate mechanisms of change, and provide important feedback which can be used to modify or expand programs.

Despite the potential utility of conducting program evaluations, there have been a limited number of program evaluations of camps for chronically ill children;⁹ of those that have been conducted, few have been able to include child perspectives as well as parents' in the evaluation, satisfaction with the camp experience once campers and their families have returned to their daily lives, or certain chronic illness populations (e.g., children with cancer).

Overall, previous camp evaluations have evaluated pediatric chronic illness camps in order to determine whether camps are meeting their own outlined goals and whether camps more generally help children develop more adaptive or positive attitudes related to illness.¹⁰ For example, Tiemens et al. evaluated a camp for adolescents with a craniofacial difference (CFD) which aimed to provide social support to campers through such means as promoting discussion between campers about shared experiences.¹¹ Similarly, Hunter et al. examined whether a diabetes camp was meeting its mission statements which included the goals of increasing self-management skills, enhancing emotional adjustment, and enhancing

self-esteem in campers.¹² Additionally, Kiernan and MacLachlan examined an international summer camp for chronically ill children and found that camper preferences for camp components and activities can be strongly influenced by age or gender which suggests that camps can be organized and tailored to meet campers' interests.¹³

The results of existing camp evaluations generally suggest that the camp experience may be beneficial for chronically ill children.¹⁴ For example, Briery and Rabian examined the impact of a summer camp for chronically ill children on children's attitudes toward illness and found that children reported more positive attitudes at the end of camp than at the start.¹⁵ Results of other studies suggest benefits of camp include reduced isolation and increased self-esteem.¹⁶

When considering the general findings of previous camp evaluations it is important to acknowledge that most published camp evaluations have not been able to assess both parent and camper perspectives of camp experience and have not assessed parent and camper satisfaction with the camp experience upon their return to their daily lives. Furthermore, the majority of existing camp evaluations were not able to assess how camp is helpful to campers or the reasons children enjoy attending camp. Also, there have been a limited number of studies evaluating camps for children with cancer and camps for siblings of chronically ill children. Additionally, many of the existing evaluations in the literature have administered questionnaires on-site and within a month of camp termination. The limited number of published evaluations of camps for children with cancer and their families is of concern given that a majority of the states in the country have at least one pediatric

oncology camp.¹⁷

PURPOSE OF STUDY

Due to the potential benefits of program evaluation for campers, families, and organizations, the current program evaluation was conducted with the aim of providing feedback to camp organizers and assessing whether outcomes meet camp goals. Specifically, the current study is a program evaluation of Camp Okizu, a summer camp for pediatric oncology patients and their siblings. The evaluation assessed parent and camper satisfaction with the camp and solicited suggested improvements. Notably, the current study incorporates both camper (oncology patients and their siblings) and parent perspectives, and assesses satisfaction with camp experience, helpfulness of camp, and reasons children like camp at least two months after camp sessions conclude. Additionally, current project aimed to determine if administering mail-based surveys was a sufficient method of assessment.

METHODS

PARTICIPANTS

Participants in the current study were children with cancer, siblings of children with cancer, and their parents. Children ranged in age from 5 to 18 (average age of children with cancer = 12.7, SD = 3.06; average age of siblings = 11.6, SD = 2.9). Participants were recruited from Camp Okizu, a camp for pediatric oncology patients and siblings of pediatric oncology patients. Campers are referred to Camp Okizu by medical treatment teams in Northern California medical centers. Children are eligible to attend Camp Okizu if they either currently have, or are survivors of, cancer, as well as children who have a sibling with cancer or had a sibling who died from cancer.

Eighty-nine families participated

in the current study (56 children with cancer, 73 siblings of children with cancer (8 children with deceased oncology patient siblings), and 87 parents (78 mothers, 9 fathers). Fifty-eight male (45.0%) and 71 female (55.0%) campers participated in the study. The majority of participants were White (74.2%) and the remaining participants were Black (5.5%), American Indian (3.1%), Asian (4.7%), or identified as an ethnicity not listed (12.5%). Campers attended one of eight camp sessions, with the greatest number of pediatric oncology patients attending Oncology Week 1 (21.3%) and the greatest number of siblings attending Sibs Week 1 (31.8%). The number of years that campers had attended camp ranged from 1 (23.6%) to 11 (1.6%), with the average number of years being 3.42 (SD = 2.64). The mean age of pediatric oncology patients when diagnosed was 6.9 (SD = 4.2) and the majority of patients underwent chemotherapy treatment (58.4%). The current health status for the majority of oncology patients was off treatment (89.3%), with the remaining participants' current status as on treatment (10.7%).

Forty parents indicated that they were a college graduate (44.9%), 27 parents indicated that they were a high school graduate (30.3%), 17 parents indicated that they had attained a graduate degree (19.1%), 1 parent indicated that they had received some high school education (1.1%), and 1 parent indicated that they had received a 9th grade education or less (1.1%). The median income of participating families was in the range of \$75,000 to \$99,999 (SD = \$50,000).

MEASURES

Parents completed a *Demographics Questionnaire* which included questions about socioeconomic status, ethnicity, parent education level, and number

of years each child attended camp. Furthermore, parents were asked questions about oncology patient's medical history (e.g., past treatment, current health status, and child's age of diagnosis).

All campers (both siblings and children with cancer) completed a *Camp Evaluation Survey for Campers*. The Camp Evaluation Survey for Campers was created for the current study based on the camp's mission statement and with feedback from camp administration. The measure consists of 26 items and assesses camper satisfaction with camp experience and reasons campers like the camp. Campers were asked to rate camp activities (e.g., cabin group activities, waterfront activities, special events, etc.) and aspects of camp (e.g., the food, counselors, and camp staff) on a five-point Likert scale ranging from "really liked" to "really disliked." Smiley faces (in addition to word ratings) were used to assist children in rating their responses to questions. Additionally, the campers were asked open-ended questions about friendships at camp as well as what could be done to make camp better.

Based on the camp's mission statement, three subscales were created to assess camper satisfaction, in addition to an overall total score for camper satisfaction. The subscales were satisfaction with Recreation, Peer Support, and Camp Features (e.g., staff and food). The Recreation subscale consisted of five items related to events and activities (e.g., waterfront activities, special events, special interest activities, cabin group activities, and night time activities). The Peer Support subscale consisted of three items and assessed camper satisfaction with cabin group activities, bereaved siblings group activities, and a group inspiration activity. The Camp Features subscale consisted of three items and assessed camper

satisfaction with the food, counselors, and staff at Camp Okizu.

Additionally, the Camp Evaluation for Campers assessed reasons why children like attending camp. Based on the camp's mission statement, four subscales were created to assess reasons children like camp. The subscales were Recreation, Respite, Peer Support, and Camp Features. The Recreation subscale consisted of one item and assessed whether campers viewed being outdoors as a reason for liking camp. The Respite subscale consisted of one item and assessed whether campers viewed getting a break from medical treatments as a reason for liking camp. The Peer Support subscale consisted of six items and assessed whether campers viewed making new friends, seeing old friends, being part of a bereaved siblings group, meeting other children with cancer (or other siblings of children with cancer), camp being a safe place where they can trust others, and participating in inspiration activities as reasons why they liked camp. The Camp Features subscale consisted of three items and assessed whether campers viewed the food, counselors, or other staff at camp as reasons for liking camp. Additionally, an overall total score was created which assessed campers' satisfaction with camp as well as reasons for liking camp.

All parents completed a *Camp Evaluation Survey for Parents*. Similar to the Camp Evaluation Survey for Campers, the Camp Evaluation Survey for Parents was based on the camp mission statement and feedback from camp administration. The measure consists of 20 items and assesses parent satisfaction with child(ren)'s camp experiences and helpfulness of camp. Parents were asked to rate their satisfaction with different components of camp, as well as what was helpful about camp.

In the Camp Evaluation Survey for Parents, parents rated their satisfaction with Camp Okizu in a range of areas. Based on the camp's mission statement, three subscales were created to assess parent satisfaction, in addition to an overall total score for parent satisfaction. The subscales were satisfaction with Recreation, Respite, and Camp Experience. The Recreation subscale consisted of one item and assessed parents' satisfaction with camp activities available to their child(ren). The Respite subscale consisted of three items and assessed parents' satisfaction with medical care at camp, responsiveness of camp administration, and transportation offered by camp. The Camp Features subscale consisted of three items and assessed parents' satisfaction with the food at camp, the counselors, and camp facilities.

Similarly, parents were asked questions about how helpful different aspects of camp were to their child(ren) on a five-point Likert scale ranging from "not at all" to "very much." The survey asked about parent's satisfaction with the child's camp experience with activities, food, counselors, and facilities. Parents were also asked about how helpful the camp experience was for their child(ren) in a number of domains (e.g., child's level of independence).

Based on the camp's mission statement, three subscales were created to assess reasons parents view camp as helpful. The subscales were Respite, Peer Support, and Child Improvements. The Respite subscale consisted of three items and assessed whether parents viewed knowing their child(ren) had adequate medical care, taking a break from caretaking responsibilities, and knowing their child(ren) is/are safe at camp as reasons camp is helpful. The Peer Support subscale consisted of one item and assessed if parents

viewed child(ren) being with others who understand their situation as a reason camp is helpful to their child(ren). The Child Improvements subscale consisted of three items and assessed whether parents noticed improvements after camp in their child's feelings about themselves, behavior, or level of independence and if these improvements were a reason they considered camp to be helpful. Moreover, parents were asked open-ended questions about suggested improvements, how camp is helpful to their child(ren), and general comments/feedback. Additionally, an overall total score was created which assessed both parents' satisfaction with camp as well as reasons camp is helpful.

PROCEDURE

All families who registered for camp in the summer of 2008 were mailed a cover letter describing the study, consent form, and stamped return envelope. Parents were asked to sign the consent form and return it to study investigators. Investigators resent consent materials to families who did not respond to this first mailing. Recruitment occurred in two waves; the first wave of recruitment targeted the families of all children registered for camp during summer 2008. A second wave of recruitment mailings was also conducted to ensure that all families were given an opportunity to participate. As a result of the first mailing, 78 families (87.7%) returned signed consents and 11 families (12.3%) returned consents as a result of the second mailing. Of those who returned consents (89 families, 100%) completed the study questionnaires.

Families who consented to participate in the study were mailed questionnaires after camp sessions had concluded, during the months of October and November. Parents were also provided with an assent

statement to read to children and a postage-paid return envelope for the questionnaires. All procedures for the current study were approved by the university's institutional review board.

RESULTS

CAMPER EVALUATION

Scores (mean items) on the Camp Evaluation for Campers ranged from 1 to 5, with 1 being "really liked" and 5 being "really disliked." The mean satisfaction rating across all items was 1.5 (SD = 0.4) which indicates that campers generally "really liked" to "liked" camp. On average, camper ratings on the Recreation subscale items were 1.4 (SD = 0.4), and on the Camp Features subscale items were which averaged 1.4 (SD = 0.4), indicating that campers generally "liked" to "really liked" recreational aspects of camp as well as basics of the camp experience. Of the subscales, the Peer Support had the highest average of all subscales, with an average of 1.7 (SD = 0.7) which indicates that campers generally "liked" to "really liked" the peer support aspects of camp.

On average, camper ratings for the reasons that campers liked camp was assessed on the Recreation subscale items, which were 1.5 (SD = 0.7), on the Peer Support subscale items, which were 1.5 (SD = 0.6), and on the Camp Features subscale items, which were 1.4 (SD = 0.5), indicating that campers generally viewed recreation at camp, peer support at camp, and features of the camp experience as reasons they "liked" to "really liked" camp. Of the subscales, Respite had the highest average, with an average of 1.7 (SD = 0.8) which indicates that campers generally view respite as a reason they "liked" to "really liked" camp.

An overall total score which assessed campers' satisfaction with

camp as well as reasons for liking camp averaged 1.5 (SD = 0.4) which indicates that campers generally "liked" to "really liked" camp and could identify reasons that they liked camp.

PARENT EVALUATION

Scores (mean items) on the Camp Evaluation for Parents ranged from 1 to 4, with 1 being "very dissatisfied" and 4 being "very satisfied." The mean satisfaction rating across all items was 3.5 (SD = 0.9) which indicates that parents were generally "satisfied" to "very satisfied." Of the subscales, Recreation had the highest average satisfaction level, with an average of 3.6 (SD = 1.0) which indicates that parents were generally "satisfied" to "very satisfied." On average, parent ratings on the Respite subscale items were 3.5 (SD = 0.9) and on the Camp Features subscale items were 3.5 (SD = 0.9), indicating that parents were generally "satisfied" to "very satisfied" with respite as well as features of the camp.

Scores (mean items) on the section of the evaluation assessing reasons parents view camp as helpful ranged from 1 to 5, with 1 being "not at all" and 4 being "very helpful." Of the subscales, Peer Support had the highest average rating (M = 4.0, SD = 0.3) which indicates that parents considered peer support as "very much" a reason why camp is helpful to their child(ren). On average, parent ratings on the Respite subscale items were 3.7 (SD = 0.5), and on the Child Improvements subscale items were 3.6 (SD = 0.5), indicating that parents viewed child improvements after camp and respite as "somewhat" to "very much" reasons why camp is helpful.

An overall total score which assessed parents' satisfaction with camp as well as reasons camp is helpful averaged 4.14 (SD = 0.71) which indicates that overall parents

were generally satisfied with the camp and found that many features of camp were helpful to their children.

QUALITATIVE DATA

At the conclusion of the Camp Evaluation for both Parents and Campers were open-ended questions designed to solicit feedback and suggestions for camp improvement. When asked what were reasons for returning to camp each year a large number of campers stated that getting away from home, the supportive and understanding atmosphere of camp, and the feeling of belonging between campers were reasons they kept coming back. Campers frequently reported that they learned new skills at camp ranging from making friendship bracelets and kayaking to acquiring leadership skills and being open to others. Parents reported that the main reasons camp was helpful to their children include the level of peer support and understanding among campers, the confidence and independence boost, and the escape from stressful daily life.

DISCUSSION

Overall, parent and child satisfaction with camp ratings were between “satisfied” and “very satisfied” suggesting that camp is viewed as positive and helpful by the majority of campers and their families. Child satisfaction ratings, as well as reasons for liking camp, indicated that children were most satisfied with aspects of the overall camp experience (which included food, staff, counselors, and facilities). Out of the four subscales assessed on the evaluation, campers consistently rated camp experience highest on satisfaction and as a reason for liking camp which suggests that campers enjoy and are happy with the environment of summer camp. Parent satisfaction responses indicated that parents were most satisfied

with aspects of camp related to child and parent relief from daily stress, whereas in terms of the reasons parents think camp is helpful, parents rated peer support the highest. One aspect of camp that is related to peer support in the activity of Inspiration. This is a time when the entire camp comes together to acknowledge that everyone there has had cancer affect them or their family. It is a time when campers can talk openly about their experiences or simply listen to others.

In addition, child responses on the satisfaction survey indicated that children were least satisfied with peer support; however ratings on the Peer Support subscale were still fairly high. As for reasons children liked camp, aspects of camp related to the Respite subscale were rated low, indicating that children generally “neither liked nor disliked” to “disliked” relief from daily life while at camp.

An additional suggestion of the current study is that it appears that the process of assessing parent and camper satisfaction through mail-based surveys is a feasible method for obtaining feedback relevant to chronic illness summer camps and specifically, conducting program evaluations.

There is some disagreement in the findings between what parents view as helpful about camp and what children actually like about attending camp. For example, parents view peer support as the highest rated of all the reasons camp is helpful to campers. This perception by parents is not held by children either in terms of camper satisfaction with different aspects of camp, in which campers rate peer support lower than overall camp experience, or in terms of reasons for liking camp, in which children rate peer support as being equal to recreation and least favorable of the camper satisfaction subscales.

There are several possible explanations for the discrepancy

between parent and child perspectives on camp. First, parents might view campers meeting other campers who can empathize and understand what they have been through as the most beneficial feature of camp; however, campers rate camp experience the highest suggesting that they view camp as valuable simply by being able to go and have a fun week away from their daily lives. Second, perhaps differences in the evaluation scales are responsible for the disagreement between parent and child(ren) report. That is, parents evaluated camp on how satisfied they were and reasons camp was helpful, whereas children evaluated camp on how satisfied they were and reasons they liked camp. Thus, the difference between parent and child responses might be due to the fact that what children like about camp and what about camp is helpful are two separate constructs.

The current study's findings differ somewhat from those of previous studies. In a camp evaluation by Hunter et al., results indicated that camp goals to increase camper self-management skills and self esteem were not fully supported.¹⁸ However, in the current study, results suggest that camp is successful in meeting its goals based on high camper and parent satisfaction on the subscales of Recreation, Respite, and Peer Support. In another study, Tiemens et al. concluded that the use of social group work or peer support and peer understanding are promising components to be incorporated into future interventions for adolescents with a CFD.¹⁹ This contrasts with the current study because peer support was not rated highest by campers as a reason for liking camp or as an aspect of camp with which they were satisfied. (However, it is interesting that open-ended responses from campers and parents included peer support as an important feature of

camp.) Perhaps children affected by cancer and their families are more interested in having fun and getting a break from daily life than in meeting peers who understand what they have been through.

Additionally, it is possible that the methodology of the current study contributed to findings that are dissimilar from those in the existing literature. For example, the current project is one of the first studies to include both parent and camper perspectives. Perhaps the method of incorporating both parent and camper evaluations enables a more accurate sense of camp satisfaction by examining differences or similarities between the two reports and attempting to determine reasons for their existence. Multisource data assists in reducing the possibility of biased responses as well as enabling investigators to negate alternative explanations for results.²⁰

The results of the current study should be interpreted with several limitations in mind. The current study is limited by the absence of two subscales on the evaluation forms. Specifically, the subscale of Peer Support was not assessed on the satisfaction component of the Camp Evaluation for Parents and the subscale of Respite is not assessed on the reasons why campers like camp component of the Camp Evaluation for Campers. Parent satisfaction was not assessed on the Peer Support aspects of camp because we expected campers to be the best reporters of their own perceived level of peer support; however, future research might incorporate parent perceptions of satisfaction with child peer support at camp. The current study operationalized Respite differently for parents and campers. Respite for parents incorporated features of camp which allowed parents a break from care-taking responsibilities

whereas respite for campers was operationalized as receiving a break from medical treatment. In order to streamline the questionnaire, Respite was not assessed for reasons campers liked camp because the majority of campers were off-treatment. Future research should aim to replicate the current evaluation with other camps of similar illness or with camps with a different structure. Future studies will also need to replicate the current results in more economically and ethnically diverse samples. Additionally, determining possible reasons that this camp does not serve more economically and ethnically diverse samples would be important in order to maximize camp outreach and overall effectiveness. For example, do children from all socio-economic backgrounds have the option to attend camp or do those from lower socio-economic families not get referred as often.

The current program evaluation has the potential to help improve the services of Camp Okizu by assisting camp administration in efforts to more effectively meet camp goals. The feedback received from both parents and campers offer suggestions to enhance components of camp in order to make activities available more diverse or more fitted to the interests of the consumers. For example, campers proposed numerous ideas for new special interest activities to be offered at camp (e.g., cooking/fun with foods, boating/fishing, dance/yoga, and art/drama). This particular suggestion might serve to better meet

the camp's aim to provide recreational opportunities to campers by offering a variety of activities in which previous campers have expressed interest. Parents and campers also reported suggestions to improve camp design in other ways.

Campers most commonly suggested more special interest time, longer sessions, access to ropes course for all ages, and availability of more teenage activities. Parents' suggestions had several areas of overlap with campers'; parents proposed creating longer sessions, offering a winter session, making better tasting and healthier food available, and helping families stay in contact (e.g., providing a camper contact information sheet to parents so that young children are able to keep in touch with other campers with the help of parents or posting pictures of campers on camp website so that parents can keep updated on what is going on). It is possible that these improvements will not only increase parent and camper satisfaction with the camp experience but the alterations may also serve to further Camp Okizu in fulfilling their mission statement.

Future evaluations should aim to systematically evaluate camps in order to improve outcomes by including camper and parent reports in the evaluation and by careful examination of aspects of camp that both campers and parents view as beneficial so that camps can build upon existing components which families identify as beneficial as well as so that camps can continue to improve their services.

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