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Camping programs for children with cancer and their families

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Abstract This paper presents an introduction to the role of camping programs for children with cancer and their families and a hypothesized theory of action. Nine previously published studies investigating recreation-based summer camps for children with cancer and their families are summarized. Overall, these programs appear to be effective; however, an overall conclusion is difficult to state due to variations in design, heterogeneity of subjects, and differences in the definition of camp programs. The lack of knowledge regarding the efficacy of these pro-

grams is identified as the largest deficiency in the current literature on this topic. Future research needs in this area are discussed.

Keywords Childhood cancer · Therapeutic recreation · Camping

Introduction

Psychosocial support programs exist to support families through childhood cancer. One such program is the recreation-based summer camp. Since the first camp for children with cancer in Florida, USA, in 1976, more than 60 summer camps have been established worldwide [12, 27]. Although these camps are popular, to date little documentation exists in peer-reviewed journals on their existence, and little systematic evaluation of risk-benefit has been conducted [1, 48, 58].

Together with the advent of psychosocial programs to support families, there have been changes in health care. With these current changes, there has been an increased demand for accountability and outcome-driven, cost-effective models of care [32]. It is now time to better understand the existence and role of recreational camping programs in order that future research into the efficacy of these programs is conducted [14, 19, 21, 33, 37, 44]. This paper is the first to review what is currently known about recreation-based summer camping for children

with cancer and will also include a specific discussion regarding these camps in Canada.

Literature on therapeutic recreation will be presented to introduce the field and thereby provide background for the theoretical role of camping for this population. Second, literature on social support will be discussed. It is hypothesized that psychosocial programs such as summer camps may have beneficial outcomes due to their provision of social support. Third, a literature review of previous studies on cancer camping is provided. Last, a section on future directions for research is discussed.

Significance of problem

Every year in Canada alone, about 1,250 children (ages 0–19) are diagnosed with cancer [16]. This fact results in well over 2,000 new siblings who are affected by childhood cancer in Canada each year. Knowledge has existed for several decades that people under stress are more susceptible to illness, depression, anxiety, low self-confi-

dence, and dissatisfaction with life than are people not experiencing stress [5, 42]. It is no surprise, therefore, that this is also the case for the pediatric oncology population. It is well known that childhood cancer patients and their families experience stress that leaves them at risk of developing long-term physical, emotional, and psychosocial problems [24, 25, 26, 31, 33, 36, 37, 51, 59]. In fact, when considering the entire family affected by childhood cancer, it is the siblings who are likely the most emotionally disregarded and distressed of all family members [35, 53].

There is a growing perception that the psychosocial needs of the healthy siblings of children with cancer are less sufficiently met than those of other members of the family [18, 37, 46, 54, 55]. Although less is known about quality of life (QOL) in pediatric populations, it is hypothesized that these stresses associated with the childhood cancer experience contribute to lower QOL for patients and siblings. This is especially important for children, since QOL is not simply related to contentment with life but also forms the basis for cognitive and emotional development [45]. Although a good understanding of the stresses experienced by families affected by childhood cancer exists, there is a need to better understand the existence, and in the future, the efficacy, of interventions such as camping programs that aim to reduce stress in pediatric oncology populations, especially those interventions that focus on the entire family [24].

Therapeutic recreation

Therapeutic recreation is defined as purposeful intervention designed to improve the participant's QOL through recreation and leisure [28]. Other terms used synonymously with therapeutic recreation include clinical therapeutic recreation and recreation therapy [6]. The theory that recreation serves important functions is not new. Freud in 1955, Erikson in 1963, and Bolig in 1980 wrote about recreation and its role in helping children master anxiety-producing events and learn to cope with experiences, thereby contributing to QOL [3]. Recreation-based summer camps are one form of therapeutic recreation. These camps are typically 6–12 days long for older children (usually over 7 years) and involve sleeping away from home in a wilderness setting with approximately 20–100 other children. Programs at these summer camps may include canoeing, music and drama, swimming, boating, hiking, high ropes climbing, kayaking, earth education, horseback riding, campfires, out-trips, arts and crafts, and other similar programs.

Typical goals stated for therapeutic recreation interventions include improving QOL, developing emotional stability, increasing interpersonal/social skills, developing feelings of competence, increasing feelings of belonging, decreasing stress, improving physical fitness,

self efficacy, perceived control, pleasure, enjoyment, and developing positive self esteem [6, 8, 10, 15, 41]. Summer camps have become a popular type of therapeutic recreation that aim to address the various psychosocial needs of children. Camps have been developed for children with cancer, HIV/AIDS, diabetes, obesity, learning disabilities, and other special needs [14].

Improved rates of survival for those diagnosed with childhood cancer in the 1970s led to the establishment of the first summer camp for children with cancer in Florida, USA, in 1976 [27]. This camp was organized as an outdoor recreation program and was felt to be an important part of the patient's psychosocial rehabilitation. An article published about this first cancer camp stated that meeting other children with cancer and the independence gained by the child were beneficial but that more vigorous psychological testing would be an asset to future assessments of camping programs [27].

To date, there are nine camps for children with cancer and their families in Canada. Camp Trillium is the largest of these, both in Canada and worldwide, serving 2,500 campers per year. Maher, a founder of the first cancer camp program in Canada, published a document stating the goals of these camps. They are to: (1) help children make new friends and to catch up on social interaction skills that cancer in the family denied them; (2) help children learn new skills; (3) help children become more independent and confident and to improve their self-image and sense of control in hopes that this greater sense of self worth may translate into better coping skills and therefore less dependence on health care providers; (4) help children work together with others in order to nurture new friendships and therefore enlarge the child's support network; (5) enable children to meet others who are sharing similar life experiences; (6) help siblings from feeling left out of the family experiences; and (7) help bereaved siblings realize they can have fun again [34]. Maher developed camp with the belief that mutual self-help between children in similar life situations works. He felt that camp would be the place where children could share their anger, frustration, fear, loneliness, or guilt with others and realize that it is normal to have those feelings. He felt that mutual self-help occurs inevitably when children talk and play together at camp.

Although not yet quantitatively researched, it is felt that "learning new skills at camp increases [children's] confidence and improves their self-image, giving them a greater sense of control and responsibility in their lives" [9]. Summer camps aim to provide positive experiences through activity in order that children may become more resistant to the stresses in their lives [34]. It has also been said that camp gives children opportunities by taking part in new activities and that this may increase their self esteem [34]. However, one of the most important aspects that camp offers is the opportunity for patients and siblings affected by childhood cancer to be children [26].

Social support

Previous research has indicated a need for social support for patients and siblings to provide information, opportunities to express their own feelings, attention to maintain their self-esteem, reassurance to avoid fear and guilt, as well as practical support to help children keep up their own interests and activities [35, 50, 51, 56]. It has been hypothesized that camp improves the psychosocial adjustment of its participants through its role as a social support [33, 35, 37]. Although social in nature, it is not yet clear if camp is a social support intervention or if it exerts its effects through other mechanisms.

A conceptual framework of social support has been developed by House and includes emotional support (listening, empathy, encouragement, love, and trust); instrumental support (direct help with respect to time or materials); and informational support and appraisal support (self-evaluation, comparison, and affirmation that one's interpretations are appropriate) [22]. The literature indicates that emotional support seems to protect individuals from the negative consequences of stress by reinforcing their sense of self-esteem. A strong self-esteem will help the individual mobilize coping resources. Instrumental support can lessen the burden of a stressor, and informational support helps to clarify misunderstandings individuals may have. Appraisal support may also help strengthen self-esteem by helping individuals interpret stressful situations more appropriately by helping to decrease fears and misconceptions [5, 38]. Based on definitions of social support and an informal appraisal of camp activities, it seems plausible that camp exerts its effects through its role as a social support for families affected by childhood cancer.

Previous research on cancer camp programs

To date, nine studies have been conducted investigating recreation-based summer camps for children affected by cancer; one study has been conducted investigating camps for adults with cancer [58]. Regarding research on children's camp programs, three of these studied cancer patients only [11, 13, 29], three included siblings in the study population or studied siblings alone [39, 49, 52], and two studied the entire family [7, 48]. These studies are outlined in Table 1. The discussion is restricted to research papers; autobiographical accounts of experiences at camp are not included.

The first study published in 1985 by Kessell et al. examined a wilderness Outward Bound program for adolescents with cancer and other illnesses or disabilities [29]. This study aimed to examine locus of control, self-image, family environment, and family dynamics. Measurements were obtained using the Offer Self-Image Questionnaire for Adolescents, the Nowicki-Strickland

Personal Reaction Survey (locus of control), and the Moos Family Environment Scale. Measurements were taken at three time points—precamp, 2 weeks postcamp, and 6 weeks postcamp. Significant increases in internal locus of control and body image were found. As well, family conflict declined and recreational involvement with peers increased. Of the 23 adolescents eligible, 17 participated. However, the authors did not specify how many of these adolescents had cancer versus other disorders. Strengths of this study include the use of reliable, valid scales for measurement of outcomes and use of a nonparametric analysis in order to deal with the nonnormal distribution of data arising from the small sample size used.

The second study published in 1987 by Benson used a quasiexperimental design to determine the association between a summer camping program and self-concept in children with cancer [11]. The sample consisted of 14 campers. Subjects completed the Piers-Harris Children's Self-Concept Scale and drew pictures of their friends pre- and postcamp. *T* tests were used to compare pre- and postcamp means, and the drawings were scored by the Kinetic Family Drawings Scale Revised. Self-concept did not change significantly after camp; however, the pre- and postcamp drawings were significantly different. Significant subscale scores for the drawings were self-image (0.03, $p < 0.05$) and emotional tone (0.01, $p < 0.05$). This study was limited by its lack of random sampling, small sample size, and lack of an external control group.

The third study published in 1987 by Smith et al. assessed the effects of a 1-week camp on daily activity and family interactions for patients and siblings [52]. Eighteen campers participated and completed questionnaires 2 weeks prior to camp as well as 2 weeks and 1 month after camp. The Interaction With Environment Checklist and the Daily Activity Scale (developed for this study) were used to assess the amount of time the child spent in physical, social, and self-engaged activities. Statistically significant changes were observed after camp in the amount of time children spent in those activities. All changes were in the positive direction and remained at 1 month follow-up, except for improvements in physical activity, which was only maintained for 2 weeks following camp. Also, interactions with others as well as own family increased following camp, except for siblings, whose interactions with others was significantly lower postcamp. Strengths of this study include testing and follow-ups on all 18 participants, and repeated measures were appropriately taken into account in the analysis due to the use of multiple assessments for each subject. However, this study is limited by the fact that there was no control group and the sample size was small and not randomly selected.

The fourth study published in 1989 by Sahler and Carpenter used a naturalistic design to evaluate the effect

Table 1 Previous research on cancer camp programs for children and families

Authors	Study design and data collection	N	Population	Objectives	Results	Limitations
Kessel M et al, 1985	Offer self-image questionnaire for adolescents, Nowicki-Strickland Personal Reaction survey (locus of control), Moos family environment scale	23	Ill or disabled adolescents (including cancer patients) Outward Bound and the University of Minnesota	Locus of control, self-image, family environment and family dynamics	Significant increase in internal locus of control, body image, family conflict declined, and recreational involvement with peers increased, while involvement with family decreased	No control group. Number with cancer in sample not specified. Small sample size. Six adolescents did not complete questionnaires
Benson P, 1987	Quasiexperimental design, Piers-Harris children's self-concept scale and kinetic family drawings scale-R	14	Cancer patients, 7–18 years	Ascertain association between summer camping program and self-concept	No significant changes in self-concept. Comparisons of the pre- and postcamp drawings were significant, subscale scores were self-image (.027, $p < .05$) and emotional tone (.013, $p < .05$)	No external control group. Small sample size
Smith KE et al, 1987	Interaction with environment checklist (self report) and daily activity scale (developed for this study)	18	Patients and siblings 5–12 years, Children's Hospital of Birmingham, Alabama	Assess effects of camp on which activities were engaged in during camp and amount of time spent engaged in these activities	Statistically significant changes after camp in amount of time children spent in social, physical and self-engaged activities. Statistically significant changes in interactions with family and others post-camp were observed	No control group. Small sample size. Not a random sample
Sahler OJZ, Carpenter PJ, 1989; Carpenter PJ, Sahler OJZ, 1989	Naturalistic study design using pre- and posttests	90	Siblings of cancer patients 6–17 years attending "Camp Brothers and Sisters Together," University of Rochester, New York, USA	Level of medical knowledge, perceptions of cancer effects on the individual and on the participant's mood state	Desirable changes occurred in three areas: medical knowledge, perceptions of cancer experiences, and mood state, and were sustained for at least 3 months after camp. Desirable changes most pronounced in siblings with behavioral problems	No control group. Analyses did not taking into account clustering. Of camper population, only 65% completed pre-and posttests
Bluebond-Langer M et al, 1990	Case study and quasi-experimental design. Open-ended interviews 1 month before and 6 months after the camp (parent and child). Participant observation by an anthropologist and a social worker at camp and for 2 years after in treatment centres	50	Cancer patients 8–18 years attending Camp Can-Do, Pennsylvania, USA	Whether cancer and its treatment are informally discussed by children at camp, what kinds of information are exchanged during these discussions, how these interactions might affect the children's understanding of	Despite the lack of formal instruction, there was a significant increase in children's knowledge of cancer and its treatment. Age, gender, diagnosis, years since diagnosis, treatment status, and times at camp were not found to be significant determinants of	No control group. Interviewers not blinded to study hypotheses. Of the total eligible camper population, only 65% participated

Table 1 (continued)

Authors	Study design and data collection	N	Population	Objectives	Results	Limitations
Bluebond-Langer M et al, 1991	Same as above	50	Same as above	cancer and its treatment Children's views of camp, their knowledge and attitudes toward their disease, their relationships with peers, and the impact of camp on these aspects	gain of knowledge. Younger children and those diagnosed within 1 year had largest gains in knowledge Children went to camp to have a good time and make new friends, majority of children kept in touch after camp. Empathy, understanding and acceptance main benefits expressed to having a friend who also had cancer, camp friendships a source of information about cancer	Same as above
Ruffin JE et al, 1997	19-item questionnaire to evaluate program given to participants	11 families	Families from Richland Memorial Hospital, Columbia, South Carolina, USA	Assessed if the family weekend retreat met family's needs for education, recreation, and mutual support	All the responses were positive to the questions posed. The most positive responses were given for questions regarding mutual support between families	No control group. Small sample size. Subjects not blinded to objectives
Balen R et al, 1998	Questionnaire	220	Parents of children 9–16 years, Britain	Who applies to attend camp, what factors are considered by families when they are deciding whether to send their child to camp	Camp appeals to children who are confident, active, able to separate from parents, further from diagnosis. No significant differences by demographic characteristics (age, gender, or diagnosis)	No control group. Only 60% response rate. Sample size limited in subanalyses
Murray JS, 2001	Descriptive, exploratory design, PAIC Personal Attribute Inventory for Children	50	Siblings, 7–12 years, South-Western USA	Examine self-concept in siblings of children with cancer who attended summer camp	Healthy siblings who attended summer camp scored higher on the PAIC than healthy siblings who did not attend camp	Not a random sample. No baseline information using pre-camp questionnaire

of a sibling camping program on the level of medical knowledge, perceptions of cancer, and participants' mood state [17, 49]. The camping program provided was recreational but also included formal workshops on medical topics as well as formal psychosocial support sessions. Ninety siblings completed questionnaires before and after camp. The questionnaires were designed for this study and assessed medical knowledge, perceptions of cancer, and participants' mood state. Parents were

also asked to complete a questionnaire that asked if the sibling had any problems at home or school and to rate their child's mood state. Paired *t* tests were used to compare pre- and postcamp responses. At a *p* value of <0.05, significant differences were observed for the increase in medical knowledge, intrapersonal perceptions of cancer, and camper and parent reported mood states. Younger children scored significantly lower on medical knowledge at both baseline and follow-up questionnaires; how-

ever, they were more likely to improve their scores compared to older children, and time since diagnosis was not independently related to level of knowledge. Children with previously identified problems adapting to the cancer diagnosis did not show as large improvements in knowledge as those without adaptation problems. There were no differences found based on previous camp experience. This study has several strengths, which include the inclusion of covariates, use of a rigorously developed questionnaire, and an adequate response rate for precamp questionnaires (141 out of 150 eligible campers participated). However, the study is limited by its lack of a control group, its less-than-adequate follow-up (only 65% completed both pre- and postquestionnaires), and its failure to take into account clustering in the analysis that could have led to spuriously low *p* values.

The fifth and sixth studies published in 1990 and 1991 respectively by Bluebond-Langer et al. were conducted on the same population by the same authors but investigated different outcomes. Both used a combination of case study and quasiexperimental designs enrolling 50 campers with cancer [13]. Data was collected using ethnographic field observations and structured, open-ended interviews with the children 1 month before and 6 months after camp, as well as a parent questionnaire before and after camp. The first study aimed to determine whether cancer and its treatment was informally discussed by children at camp, what kind of information was exchanged during these discussions, and how these interactions might effect the children's understanding of cancer and its treatment [13]. Ethnographic results showed that children engaged in informal discussions of cancer and its treatment and that information on a variety of topics ranging from medical procedures to prognosis was exchanged. Results from the interviews demonstrated that despite the lack of formal instruction, there was a significant increase in children's knowledge of cancer and its treatment. The covariates—age, gender, diagnosis, years since diagnosis, treatment status, and number of times at camp—were not found to be significant determinants of gain in knowledge. The hypothesis that knowledge is important has been supported by other authors who have suggested that knowledge gained at camp may help a child's social and emotional adjustment [28].

The second study, conducted at the same time, by Bluebond-Langer et al [13] aimed to investigate the peer relationships developed among campers. Interviews were used to assess the children's views of camp, their relationships with their peers, and the impact of camp on these aspects. Results showed that 26% of the children counted their camp friends among their best friends, and 54% of the children stayed in touch with the friends they made at camp during the year. When a medical crisis occurred during the year, attachments made at camp and contacts after camp did not predict who would remain

connected. On the postcamp questionnaires, 32% said camp friends were a source of empathy, 20% said a source of understanding, 8% a source of acceptance, and 3% a source of hope. In contrast, 70% said that their healthy friends did not understand what they had to go through. Children also indicated disadvantages to having friends who also have cancer. These disadvantages decreased following the camp experience. The children were concerned with how to treat other patients, and feared offending them and felt uncomfortable in the company of children who were not doing as well. They were also afraid of the deaths and relapses of these friends. They also mentioned that knowing other children with cancer sparked concern about their own condition, although the data postcamp showed that concern about own condition actually decreased by 6%. Both Bluebond-Langer et al. studies [13] are limited by their methods in that only 59% of the total camper population was included in the study due to geographic proximity to the interviewers, and no control group was studied. However, trained interviewers and observers were used for data collection. Interviewers were not blinded to study hypotheses but the transcription process was blinded and had 94% agreement on coding.

A seventh study published in 1997 by Ruffin et al. investigated a family retreat program and used a questionnaire to assess if the family weekend met the family's needs for education, recreation, and mutual support [48]. Subjects were families in which a child was diagnosed with cancer within 1 year. Eleven families participated. All responses were positive to questions posed. The most positive responses were given for questions regarding mutual support between families. Families also indicated they enjoyed both formal and informal sessions during the program. Any conclusions to be drawn from this study are extremely limited, however, by several weaknesses in study design. To begin, subjects were the same families who helped plan the program, families were not selected at random, there was no control group, and the sample size was small.

The eighth study published, in 1998 by Balen et al. researching children's cancer camps, aimed to determine who applies to attend camp in Britain and who does not, and what factors are considered by families when they are deciding whether to send their child to camp [7]. Parents ($n=220$) of children diagnosed with cancer were sent a questionnaire including demographic items, Likert scales for factors considered when deciding whether to go to camp or not, as well as questions about the child's activities. This study showed that a week of camping appeals to children who are confident, active, and able to separate from parents, and parents who are keen to encourage independence and new experiences. Children diagnosed and treated at a younger age and are further away from treatment are more likely not to apply citing safety concerns and homesickness. There were no differ-

ences in the families who were interested in camp and those who were not by demographic characteristics (age, gender, or diagnosis). The results of this study are limited in that authors obtained a response rate of only 60%, and the sample size accrued was not sufficient for the subanalyses they conducted.

The ninth and last study published in 2001 by Murray using a descriptive design enrolled a purposive sample of 50 siblings of children with cancer to examine their self-concept [39]. Of these healthy siblings, 44% ($n=22$) attended summer camp. The Personal Attribute Inventory for Children (PAIC) was used to measure self-concept, and a separate questionnaire was developed to collect information on demographics. Results of an independent sample *t* test indicated that healthy siblings who attended summer camp for siblings of children with cancer scored significantly higher on the PAIC than healthy siblings who did not attend camp. Because only postcamp questionnaires were conducted, it is essential to realize that these results could be indicating that siblings with higher self-concept chose to attend camp and siblings with lower self-concept chose not to attend. This study is the only investigation of cancer camp programming that used a control group, a standardized measure, and had sufficient sample size to obtain significant differences. However, this study failed to conduct the PAIC prior to the camp program, making it difficult to draw conclusions from their results.

In summary, evaluations of camping programs for children with cancer and their families appear to demonstrate at least short-term effects for increases in self-esteem/self-image, friendships, knowledge about cancer, level of activity, positive mood state, locus of control, and improved family functioning. Published studies to date, however, have several methodological weaknesses that make it difficult to draw conclusions from their results. Although the articles cited were published between 1985 and 2001, there appears to be no move towards methodologically stronger studies in this topic area. To begin, as shown by Balen et al. [7] those who select to attend camp differ from those who do not. It is acknowledged that the nature of the intervention inherently makes random selection difficult; however, random sampling should be an important part of any rigorous evaluation of recreation-based camping programs for this population. As well, all studies but one failed to use a control group. Finally, previous studies are limited by insufficient sample sizes, making it difficult to answer hypotheses with statistical certainty or take into account important covariates.

International organization of camps for children with cancer

One international pediatric oncology camping organization exists. The Children's Oncology Camping Association International (COCA) is an assembly of people pro-

viding camping programs for children with cancer consisting of over 70 member camps, including those from Canada, USA, Europe, Australia, and New Zealand. The group meets annually during the fall. COCA aims to improve oncology camp programs through education, dissemination of information, and sharing of ideas and concepts relevant to camping, childhood cancer, and the impact of diagnosis on the family and the child [20]. COCA is a helpful resource on programs worldwide; however, in some cases, its information is out of date and not all-inclusive. Two other resources exist for the international cataloguing of pediatric oncology camps—Kids' Camps, and Allen's Guide [2, 30].

Discussion

Although residential camping programs for children with cancer and their families exist worldwide, involve thousands of participants, and require multimillions of dollars for their programming, little knowledge regarding these programs exists. In particular, there is a lack of knowledge regarding the existence of these programs, their goals, activities, participants, and cost. Most importantly, information on the effectiveness of these programs is lacking.

Nine published studies exist that have attempted to systematically investigate camping programs for children with cancer and their families. However, many of these studies lack sufficient sample size, random selection of subjects, control groups, and standardized measurement for outcomes of interest. Loss to follow-up is also a common problem in studies of this topic. To date, it is difficult to summarize the results of these studies due to the varying objectives and programming at these camps. However, it is likely that camping programs for children with cancer and their families have at least some positive effects and may be meeting some of their stated goals.

To the best of our knowledge, there are currently two ongoing projects researching the effects of camping programs for children with cancer and their families. The first is a study that started data collection in January 2001 run by the National Cancer Institute in the United States entitled "Psychological Benefits of a Normalized Camping Experience for Children with Cancer and HIV Infection" [40]. The second study, which has not yet begun data collection, is "The Effect and Expense of Attending Camp Trillium" and will be conducted by Barr et al. in Ontario, Canada.

In determining the effectiveness of recreation-based camping, one of the greatest challenges is obtaining a definition and measure of the outcome(s) desired. How to define and measure outcomes of interest, particularly in the camping setting, has not yet been discussed to the best of our knowledge. According to the Ottawa Charter,

health promotion interventions such as recreation-based camping should aim to help “people improve their quality of life in order to reach a state of complete physical, mental and social well-being by identifying and realizing aspirations, satisfying needs, and to learning to cope with their environment” [57]. Aligned with this, essentially as a health-promotion intervention, cancer camps most often state improved QOL as a primary objective of their camp programming. However, prior to using QOL as an outcome measure to evaluate the effectiveness of camp programs, valid, reliable measures for generic children’s QOL outside the clinical setting will need to be developed. This may be challenging, since concepts thought to make up QOL in the literature are vast and often lack an overarching framework [4, 12, 23]. Depending on the source, QOL measures may include emotional well-being, spirituality, sexuality, social functioning, family life, social supports, occupational functioning, communication, eating, functional ability, health resources, physical status, treatment satisfaction, future orientation, global ratings of health or life satisfaction, control, self-esteem, stigma, and body image [4].

Although there has been an increase in theoretical and empirical papers on the topic of QOL in past years, most of this work has involved adults rather than children, with only 19 articles on empirical generic QOL research with children [43]. This may be changing, as there has been a growing interest in measuring the well-being of children [10, 47]. With this change may come an opportunity to obtain a reliable and valid measure of QOL that may assist in part with evaluations of recreation-based camping programs for children with cancer and their families.

Future research should focus on the systematic evaluation of recreation-based camping programs. This is a

need in pediatric oncology populations but also in other special-needs populations who use this kind of programming. Systematic study of these programs will be assisted with clarification of background information regarding these programs. To begin, an understanding of the number of programs offered worldwide, the populations served, and what the programs entail will be useful. As well, the theoretical underpinnings of these programs could be more clearly developed. In order for these programs to be quantitatively evaluated, objectives and measurable outcomes need to be more clearly delineated. As well, standardized measures of these outcomes need to be used or, if none exist, developed.

Once these background components are in place, future research should aim to conduct evaluations of camping programs in a rigorous fashion ensuring the program being evaluated has clear objectives and measurable outcomes; that standardized measurement tools are to be used; that a random sample is selected, including the use of a randomly selected control groups; and that appropriate analyses are used. Long-term follow-up and the measurement of important covariates will be an asset in assessing the effects of these programs. This research may then help build the foundation for future economic analyses of these programs.

In the end, knowledge regarding residential camping programs for children with cancer and their families may demonstrate how these programs are meeting the needs of families and how camps could improve their programs to better meet those needs.

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