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Perceptions of Health Care Professionals on the Effects of Residential Summer Camp in their Patients

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ABSTRACT

Purpose: A growing body of literature exists regarding medical specialty camps for children. However, very little of the research focuses on the perspectives of healthcare providers. This study explored perceptions of pediatric healthcare providers on a medical specialty camp for children.
Design and Methods: Interviews with five volunteer physicians and five nurses were conducted and analyzed using inductive content analysis.
Results: Results showed that healthcare providers perceived camp to be a positive influence on campers' normalization and healthcare ownership, and to strengthen patient-provider relationships. Providers contextualized their assertions by discussing the settings of camp and of patients. However, providers also identified multiple barriers perceived as limiting a camp experience's ability to create lasting changes in patients' attitudes or behaviors.
Conclusions: While healthcare providers in this study perceived camp as being a positive opportunity for patients, the potential for long-lasting effects was seen to be hindered by factors external to the camp and changes in patients' attitudes or behaviors can be difficult to ascribe to the camp experience.
Practice Implications: Healthcare providers can reinforce and extend positive health behavior messages from camp at follow-up appointments. Adding inquiries about camp attendance and experiences to patients' visits can provide healthcare providers with additional insights about patients. Health outcomes before and after camp could be measured to assess change. Camps can send home patient protocols on successes and challenges.

Introduction

Children diagnosed with a chronic illness are broadly affected by the consequences of their disease, long after their illnesses pose any acute impact on their medical well-being (e.g., Ameringer, Elswick, & Smith, 2014; Patterson, McDonald, Zebrack, & Medlow, 2015; Tallen et al., 2015). Similarly, the various treatment modalities offered to these children during their illness can help shape their opinions of their disease, their healthcare teams, and of healthcare in general, potentially lasting through adulthood (Grant & Pan, 2011; Kime, McKenna, & Webster, 2013; van Staa, Jedeloo, van Meeteren, & Latour, 2011). The psychosocial impact of chronic illness continues to be a salient topic of interest in pediatric medicine because survival rates of childhood illness have improved over the past half-century (American Association For Cancer Research, 2017). For example, many forms of childhood cancer are no longer perceived as terminal illnesses, but increasingly as a chronic disease (Haluska, Jessee, & Nagy, 2002). Greater attention, both clinically and in research, has focused on the psychosocial consequences of living with a chronic illness as a child and adolescent (Kolb, 2009; Lindsay, Kingsnorth, & Hamdani, 2011; Rapley & Davidson, 2010).

As psychosocial issues have received increased attention over recent years, a variety of interventions have been developed to meet the unique needs of children and adolescents affected by their chronic illnesses. Interventions include the expansion of child life specialists in the hospital setting, an emphasis on family-centered care, support groups, and palliative care (Hicks & Lavender, 2001). These and other interventions have the capacity to support children and adolescents in building and maintaining social networks (Kraaij & Garnefski, 2012). Another way to gain psychosocial support is through recreation-based medical specialty summer camps. In the early years of this movement, Shields, Abrams, and Siegel (1985) defined the goals of these camps as developing (a) self-confidence and independence, (b) new friendships, (c) a spirit of group identity, and (d) skills and exploring interests. In subsequent years, studies have attempted to evaluate the psychosocial impact of recreational camp programs, largely through pretest-posttest study designs evaluating psychosocial concepts including quality of life or self-concept (Epstein, Stinson, & Stevens, 2005).

Results of these studies have shown improvements in social support, attitudes toward illness, and other positive outcomes from the

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perspectives of campers or their parents. For example, Conrad and Altmaier (2009) concluded that children attending summer camp for children with a cancer diagnosis reported receiving more support than children in the general population. Briery and Rabian (1999) demonstrated that children with asthma, diabetes, and spina bifida improved attitudes toward their illness and had lower levels of trait anxiety after a one-week camp program. Kiernan, Gormley, and MacLachlan (2004) found that after participating in a therapeutic recreation camp program, children reported benefits in physical symptoms, self-esteem, and quality of life. Moons et al. (2006) reported that after a three-day sports camp for children with congenital heart disease, participants reported improvements in perception of physical functioning, and role functioning in emotional and behavioral health. Wu, McPhail, Mooney, Martiniuk, and Amylon (2016) conducted a standardized multisite evaluation of summer camp for children with cancer and their siblings at 19 separate camps, reporting increased self-esteem and social functioning. Other researchers have found that positive outcomes were retained several weeks or months after the program ended (e.g., Simons et al., 2007; Wellisch, Crater, Wiley, Belin, & Weinstein, 2006). While there is good evidence of positive outcomes associated with camps, less information is available from the perspectives of people other than campers or their parents. Further, a major barrier to the use of camps as a social support treatment modality is the rather short-term effect seen in most studies (Dawson, 2017; Odar, Canter, & Roberts, 2013). More information is needed about other perspectives of potential outcomes of camp that can extend beyond the camp experience itself. Given the nature of medical specialty camps, a focus on potential healthcare-related outcomes or changes is especially needed.

Study Purpose

Some previous studies have investigated the effects of medical specialty camp experiences on self-esteem, quality of life, and social skills (e.g., Kiernan et al., 2004; Odar et al., 2013; Wu et al., 2016). However, scarce information is available regarding healthcare–related outcomes of the camp experience, including the effects of camp on children's opinions of illness or medical adherence, and their relationship with their medical team. Further, the perspectives of healthcare providers are missing in the medical specialty camp literature. As important resources in children's lives, often over several years and through health-related challenges and successes, healthcare providers are in a unique position to reflect on their perceptions of the camp experience for their patients. The purpose of this study was to explore the perceptions of pediatric healthcare providers on a medical specialty camp for patients.

Methods

Ethics

Approval was received by the Institutional Research Board at Frank H. Netter School of Medicine at Quinnipiac University and by the Research Collaboration Review Board at “Camp Joy” (pseudonym). Informed consent and assent was secured before each interview. Participant identities were protected using encrypted data between researchers and transcription services, and by making quotations anonymous.

Setting

The mission of Camp Joy is to provide opportunities for fun and friendship to children with serious illnesses, free of charge. Each summer, Camp Joy runs eight one-week camp sessions for approximately 120 children aged 7 to 15 each session. Campers participate in recreational activities such as swimming, boating, fishing, archery, horseback riding, and ropes courses. There are no explicit educational or therapeutic sessions conducted at camp.

The medical team at camp is staffed by a full-time board certified pediatric hematologist/oncologist who serves as medical director, two full-time nurses, six additional seasonal nurses, and a team of volunteer medical staff ranging from two to four physicians and five to seven nurses each session. Healthcare providers are invited to volunteer for a week or more as part of the collaborations with hospitals that refer patients to camp. Volunteering as a healthcare provider involves attending training and providing medical care and supervision to campers through the camp's infirmary or out in the cabins or program activity areas.

Procedures

A series of semi-structured qualitative interviews was the primary data collection method. Study participants were physicians and nurse practitioners who personally treated children and adolescents who attended Camp Joy for at least one summer session. Participants were selected from a convenience sample provided by the camp's medical director. The first author reached out by email to selected study participants. Willing participants were asked to read a brief description of the study and to sign an informed consent form prior to their participation and to verbally assent at the beginning of the interview.

Of the 27 healthcare professionals contacted by email for the study, two declined, and twelve agreed to participate. Thirteen did not respond. Two participants were subsequently unable to schedule an interview. All ten interviews were conducted over the phone. Immediately prior to each interview, the first author read the informed consent statement to each subject, requesting verbal consent. Study participants were notified at the beginning of each conversation that the interview was being recorded and each participant assented to the recording.

Telephone interviews lasted 20–40 min, and followed a semi-structured interview guide. The interview questions centered on the study purpose to explore the perceptions of pediatric healthcare providers about healthcare–related outcomes of the camp experience. Demographic questions were about job titles and institutions. Participants were asked about any changes observed in patients regarding patients' attitudes toward their illness, medical procedures, and their healthcare team. Participants were then asked about any changes observed in patients regarding any health-related behaviors, including medication adherence, appointment attendance, or challenging behaviors. Finally, participants were asked about their personal attendance at camp, and any changes in the patient-provider relationship that resulted from time spent at camp. Questions were mostly open ended and relied heavily on probes. Examples of questions included: “What changes, if any, have you noticed in your patients regarding their attitudes toward their illness, after spending a week at camp?” “Have you noticed any changes in medication adherence [in your patients] since returning from camp? What kind of changes?” The full interview guide is available by contacting the second author.

Data Analysis

Data from the semi-structured interviews were analyzed using inductive content analysis based on grounded theory qualitative analysis (Corbin & Strauss, 2014). This method of analysis is appropriate when building a theory on a phenomenon from content generated by data from participant interviews and has been used in other pediatric research (e.g., Naiire, Abbas, Maryam, & Shirin, 2015; Pearson, 2013; Weekes, Kagan, James, & Seboni, 1993). The analysis process included a series of steps. To begin, the first author reviewed the data from the interviews, open coding the participants' responses by assigning words or short phrases based on the meaning gleaned from reading the responses, usually through making comparisons or asking questions of the data. Next, the first author assigned broader concepts by making connections between similar or opposing views across multiple