Original Articles

Adolescent Cancer Survivors' Oncology Camp Experience

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Objective:

To date, literature has documented psychosocial benefits for adolescent cancer survivors (ACS) who attend oncology camps; however, few take a detailed look into the uniqueness of the social phenomena that occurs within the camp context. Therefore, this study utilizes an interpretive phenomenological approach to explore: (1) What is the lived support experience of adolescent cancer survivors attending a one-week oncology camp? and (2) What is the meaning of social support to adolescent cancer survivors in the context of an oncology camp?

Method:

A total of 16 ACS (ages 11 to 19) attending a week-long oncology camp participated in the study.

Results:

Key findings shed light on the importance of peer relationships with other ACS, as ACS felt a deeper connection with others who have experienced cancer, rather than others who had not.

Conclusion:

Furthermore, these interactions facilitated a positive sense of self as a cancer survivor.

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In the United States, childhood cancer diagnoses are steadily increasing (American Cancer Society, 2018). Each year in the US, there are an estimated 15,780 new diagnosed cases of childhood cancer in those aged 0 to 19 (American Childhood Cancer Organization, n.d.). As treatment becomes more effective, the survival rate for children diagnosed with cancer has reached 80% (National Cancer Institute, 2018), and in turn, the population of adolescent cancer survivors (ACS) has increased. There are currently an estimated 270,000 survivors of childhood cancer, with one in every 640 young adults (ages 20 to 39) being a childhood cancer survivor (American Childhood Cancer Organization, n.d.). As the number of ACS has increased over the last four decades, more research has emerged that focuses on psychosocial outcomes and experiences for ACS.

Psychosocial research in adolescent cancer literature has emphasized the importance of social support for ACS as they transition to life post-treatment. These findings have led researchers to explore their psychosocial experiences where a growing body of literature has documented the positive outcomes associated with attending oncology camps (Martiniuk et al., 2014; Wu et al., 2011). Although adolescent cancer literature has explored types and sources of social support and camp as a psychosocial opportunity for ACS, there is a dearth of literature on their lived social experiences in the oncology camp context. In order to address this gap in the literature, the present study will utilize an interpretive phenomenological approach to explore the meaning of the lived social experience for ACS in the context of a week-long summer oncology camp.

Theoretical Framework Symbolic Interaction Theory

In accordance with the symbolic interactionist perspective, an individual's reality is created by their social interactions, ideas, and thoughts (Stryker, 1968). The current study is informed by three concepts from the symbolic interaction theory—meaning making from interactions with others, roles, and role salience. The concept of meaning making from interactions suggests that how adolescents perceive their interactions with others, operationalized in

the current study as perceived social support, influences their behaviors. Additionally, the meaning that individuals form from their lived experiences at camp, such as interactions, activities, and communication with others, can modify their behavior (Ingoldsby et al., 2004). ACS in the oncology camp context may view camp as a time to interact with peers who have also been diagnosed with cancer and these interactions may make them feel supported (Bluebond-Langner et al., 1991). Further, an individuals' role is defined as a set of social norms for a specific situation, and individuals can have more than one (Ingoldsby et al., 2004). For ACS attending camp, their role as a fellow camper at an oncology camp influences their behavior, in that they may behave in a way that is supportive to others in the camp. Additionally, social experiences within the camp environment may provide ACS with a unique psychosocial opportunity to serve a supportive role for others and receive support as they continue to develop their identity as cancer survivors. Lastly, the concept of role salience suggests that the oncology camp context is a space where they feel attached because ACS can comfortably identify as cancer survivors.

Literature Review

Adolescent Cancer Survivor Identity Development

ACS experience many social developmental milestones during diagnosis and treatment. Depending on the severity of the diagnosis and treatment, childhood survivors spend long periods of time in the hospital or at home where they are isolated from family, peers, and normative social environments. These limited childhood social opportunities increase ACS' risk for experiencing late effects related to psychosocial issues (Cantrell & Lupinacci, 2008). As childhood cancer patients transition into cancer survivorship, some struggle to return to normal life and recover their old identity (Cantrell & Conte, 2009). Jones et al. (2011) interviewed 12 ACS and found that identity was a challenge for them, as the survivors reported feeling caught in-between their identity as cancer patients and their new identity as a survivor. In this study, the survivors had a difficult time removing themselves psychologically and physically from their previous relationships (Jones et al., 2011). Thus, for childhood cancer patients transitioning into survivorship, difficulty in changing or redeveloping their identity may occur, as they may feel forced to "reinvent" who they are (Cantrell & Conte, 2009). The results from these studies suggest that ACS may have greater difficulty discovering their identity in survivorship, as they may be experiencing a social paradox where they are not sure which social group they fit into (Jones et al., 2011).

Social Support

Although adolescence is a time when most adolescents report receiving more support from peers (i.e., same-age friends within the school setting or participating in the same activities) than parents (Steinberg, 2014), ACS literature differs. Some ACS report parental support as being im-

portant and are more satisfied with the support from parents when compared to peers (Decker, 2007; Haluska et al., 2002; Ritchie, 2001). Parental support was reported as important because parents provided consistent comfort and support (Jones et al., 2011). Alternatively, some ACS report an overall lack of support. Jones et al. (2011) found that ACS were content with the support they received during the cancer experience, but in survivorship, support from peers and medical staff declined. Overall, studies exploring sources of support for ACS highlight the importance of understanding perceptions of social support sources in survivorship and how this may be different than the treatment phase. This information can be utilized for interventions and the supportive care that ACS receive as they transition from treatment and into survivorship.

In addition to identifying sources of support for ACS, some studies focused on the type of support different sources provide. The majority of studies found that parents and peers provide emotional support (R. T. Brown et al., 2003; Deverensky et al., 1998; Dunsmore & Quine, 1995; Ritchie, 2001), with mothers identified as the main source of emotional support (Ritchie, 2001). Adolescent cancer survivors reported parents as providing informational support about cancer-related content (Dunsmore & Quine, 1995). To date, little research has utilized qualitative methodologies to gain a deeper understanding about ACS' perceptions of the sources and types of supports that are provided to them in survivorship. This information is important to explore in order to better understand the met and unmet social support needs of ACS.

Oncology Camp Experience

An increasingly popular context for youth who have been diagnosed with cancer is summer oncology camp programs. At these camps, youth experience support for developmental processes, including emotional regulation, peer relationship building, exploring emerging identities and interests, and building character, skills, and relationships (Bialeschki et al., 2007). Spending time at camp can also provide a community of peers with an important similarity, as they have all experienced a life-threatening diagnosis and share commonalities from coping with the disease during treatment and in survivorship.

In general, oncology camps seek to provide a supportive environment with an overall goal to positively impact physical, psychological, and social functioning ("COCA-I Brochure," 2014). At camp, children have the opportunity to discover and explore new interests and increase their physical and emotional skills (Martiniuk, 2003; Wu et al., 2011). The camp experience helps children cope more effectively with their illness by increasing their self-confidence and self-esteem, making new friends, and having fun (COCA, 2013). However, some studies have found a lack of change for campers, such as camp not impacting the campers' self-concept (B. B. Brown, 2004). But, it was noted, that the timing of data collection could have played a role in this, as the majority of the other studies in this review found positive effects (Conrad & Altmaier, 2009; Török et al., 2006).

Another prominent study in oncology camp research brought to light the relational challenges ACS face. Gillard & Watts (2015) found that 25% of campers reported they had lost friends or became more distant from their healthy peers because of the cancer experience. Therefore, ACS chose to attend camp in order to connect and engage in caring relationships with other ACS (Gillard & Watts, 2015). ACS also indicated camp as an environment that increased their sociability and promoted feelings of being valued, cared for, and connected to peers (Gillard & Watts, 2015). These social opportunities led to building friendships that were unique from the friendships created outside of camp. More specifically, a camper reported that a bond between two cancer patients is special because both individuals truly understand what each person endured during their cancer journey (Gillard & Watts, 2015). For ACS, healthy peers may not be the most helpful individuals providing illness-related support and feedback, as they may not fully understand how cancer affected their friends' lives. Thus, the social experience for ACS at an oncology camp provides unique opportunities to interact with peers who also experienced cancer.

Although quantitative studies found campers reported higher levels of emotional, physical, social, and self-esteem functioning following camp (Wu et al., 2011), little is known about the underlying processes and actual relational experiences of ACS within the camp context. With limited literature focused on the support needs for ACS, it is important to better understand the oncology camp setting because the social interactions may be different than everyday interactions. Therefore, we investigated the following research questions: (1) What is the lived support experience of adolescent cancer survivors attending a one-week oncology camp? and (2) What is the meaning of social support to adolescent cancer survivors in the context of an oncology camp?

Method

Design

In order to understand the lived experience of the participants, an interpretative phenomenological approach was utilized. This approach allows the researcher to uncover commonalities and differences of lived experiences or events (Starks & Trinidad, 2007). In the current study, the lived social experience of ACS at an oncology camp and how they report social support in the context of an oncology camp are explored.

Research Site

This study was conducted at an oncology camp held at a YMCA facility in the Midwest. The camp served youth ages four to 19 who currently have cancer or are in survivorship. This oncology camp was free for the campers. The one-week overnight camp served 87 adolescents and 183 younger children. Adolescent participants (ages 11 to 19) resided in 11 cabins organized by age and gender. The camp schedule was structured to provide opportunities for campers to participate in multiple recreational activities, in

addition to therapeutic activities that addressed hardships related to cancer. Some activities were organized to encourage campers to spend time with campers their own age, while others encouraged campers interacting with other age groups. Medical staff members (i.e., doctors, nurses, a psychiatrist, and a child life specialist) who were associated with local pediatric cancer units were on-site at all times during the week to provide full medical services.

Participants

Sixteen ACS (ages 11 to 19) who attended a week-long oncology camp in the Midwest agreed to participate. To be defined as an adolescent cancer survivor in this study, the participant had to be 11 to 19 years old and had to not be undergoing any treatment to remove cancer from their body at the time. The ACS were asked to participate in the study during sign-in day on the first day of camp. Both ACS and their guardian completed an informed consent form in order to participate in the study. Fourteen of the adolescents were purposefully selected to participate in the interview, two adolescents from each cabin. Additionally, two adolescents asked to participate in interviews. A total of eight participants were female, and eight participant were male. The mean age was 14.63 years. Within this sub-sample, 15 participants were non-Hispanic, White, and one participant was African American. On average, the ACS attended camp for seven years, with the shortest amount of time attending camp being five years.

Procedures

In order to conduct this study, university institutional review approval was obtained. Interviews and observational data were collected. The interview questions encompassed open-ended questions about their camp experience and the social experiences that occur at camp. Participant interviews were conducted during unstructured activities at the end of the camp week in order for the researcher to build rapport with the camper prior to the interview. In accordance with a phenomenological research perspective, purposeful sampling was utilized (Starks & Trinidad, 2007). To maximize variety of experiences and age ranges, one to two participants from each of the seven adolescent cabins were interviewed. The other two adolescents were interviewed because they approached the principal investigator (PI) and asked to be interviewed. The camp counselors were utilized to coordinate the times that the participant could be interviewed and made suggestions as to which participant from their cabin might be the most engaged during interviews. Interviews lasted 10 to 15 minutes and were digitally recorded and transcribed verbatim. When appropriate, follow-up questions were used to probe deeper responses or to clarify information.

Additionally, informal observations were conducted in the activity areas during unstructured and structured camp activities and camp events. The PI was a participant observer each day of camp and served as an extra volunteer when needed. In the mornings, the PI spent time in the unstructured activity areas and then followed assigned cabin groups during structured activities in the afternoon. In addition, the PI attended all scheduled camp events. These informal camp observations were then used in data analysis to provide a deeper understanding of the ACS' social interactions and experiences within the weeklong camp context.

Data Sources

Demographics. The participants filled out demographic information on a survey that was also administered during the camp. Participants reported information on age, race, age diagnosed with cancer, and type of cancer diagnosis.

Social support. Five questions were asked during the interview to better understand the participants' perceptions of social support behaviors from peers, health practitioners, and social media. For example, participants were prompted with the statement, "Tell me how your friends with cancer make you feel like they care for you," and "Tell me how people at the hospital make you feel like they care for you." The participants talked about what made them feel supported.

Camp social experiences. Participants were then asked seven questions about the support they receive while at the oncology camp. Examples of participant interview questions included: "What activities at camp make you feel like people care about you?" and "Do you come to camp because it helps you feel more supported? If so, what kind of support are you wanting when you come here?"

Informal observations. In order for the researcher to better understand the camp context and ACS' social experiences in this setting, field notes were collected during the week-long camp. The field notes focused on the camp setting, unstructured and structured activities, camp events, and participants' interactions with peers and camp staff at various times throughout the day. These notes were used to provide the researcher with a deeper understanding of the social experiences described by ACS in their interviews.

Data Analysis

Each interview was audiotaped and transcribed verbatim. The data were then coded and analyzed utilizing an interpretive phenomenological framework (Pietkiewicz & Smith, 2014). Both participants' and researchers' interpretation of the phenomena was included in the process of analysis to investigate how individuals made sense of and meaning from their experiences (Smith & Osborn, 2007).

First, utilizing the eidetic method, in Phase 1 the PI read through the transcript several times to become familiar with the responses. Then, in Phase 2, the PI developed their own interpretation of the ACS' responses with some words being pulled from the transcript in addition to new words being incorporated. These notes were typically eight to 10 words. In Phase 3, the PI went through the transcript and underlined common words or phrases that encompassed the ACS' responses for each question. Once these words or phrases were underlined for each participant, a third column was developed in Phase 4 to specifically identify

meaning units (Wertz, 2005). These meaning units were essential components of the camp experience that were unique and distinguishable from other daily life phenomena for the ACS (Pietkiewicz & Smith, 2014). These meaning units were comprised of two to five words and were developed to best represent the ACS' responses, in addition to the PI's interpretation of the ACS' responses. Next, in Phase 5, the PI organized the meaning units and notes on the transcriptions into emerging themes by organizing the themes according to a conceptual similarities framework (Pietkiewicz & Smith, 2014). Then, when necessary, subthemes were added. Once the themes and subthemes were established, the PI looked for connections between the emerging themes, and grouped them into clusters according to conceptual similarities. Once each cluster was determined, a descriptive label was developed (Pietkiewicz & Smith, 2014). These descriptive labels allowed for the PI to interpret the common phenomena ACS chose to share during the interviews about their camp experience. In Phase 5, a co-author reviewed the themes to provide external audit of the emerging themes based on a reading of the transcript and notes. In addition, the PI reviewed the informal observation notes collected during camp and in each interview with the ACS, and these were incorporated into all phases of the data analysis process.

Results

Although ACS experienced personal and unique cancer journies, many of the interview responses reflected commonalities. These commonalities surfaced when they shared why oncology camp was important to them and the reasons they looked forward to continuing to attend each summer. Not only did their responses shed light on the many fulfilling social and emotional experiences that occur in the oncology camp context, but the observations throughout the week enabled deeper insight into the importance of these social interactions and how these interactions help ACS' development in many ways. The six themes that emerged through the data analysis process reveal the uniqueness of the camp phenomena: (1) survivor identity, (2), camp is a safe space, (3) peer survivors, (4) normalization, (5) confidence development, (6) home experience versus camp experience. The following themes are described in detail below.

Survivor Identity

Although the majority of ACS in this sample were diagnosed with cancer and treated in early childhood, it was clear that they view themselves as cancer survivors (n = 15). This aspect of their identity was important and a reason they chose to attend the oncology summer camp into adolescence. They felt that attending camp enabled them to experience their survivor identity, in addition to being able to better understand who they are as a survivor. This development of their survivor identity could occur because of the unique interaction opportunities ACS had with other sur-

vivor peers, younger campers, and counselors. Morgan¹ (14 years old) stated,

Like I know there's people around me that have like the same conditions and stuff like that. Like they have the same background or they've been through the same stuff...like I don't tell my friends and stuff because I don't want everybody to be like all over me about it. Because that is kind of like how people back at home are.

At camp, Morgan and many others in this sample felt comfortable speaking to survivor peers about their difficult experiences related to survivorship. In addition, the camp atmosphere was a context to validate the importance of their survivor identity, as this may not be an aspect of their identity that they are as comfortable expressing during their lives outside of camp. Jason (15 years old) shared, "I felt like sometimes [at home], I'm like, well back to being the one person that I hate being, not myself." This was the strongest word choice used in relation to the ACS' identity as a survivor, and a current struggle he faced as he navigated his identity outside of the camp context.

Furthermore, since peers at camp have a better understanding of the cancer experience and transition into survivorship, they are less likely to display a reaction in a way that ACS do not want them to. During the interviews, two other campers also expressed their hesitancy in sharing their cancer history with healthy peers because of their reactions; it appeared that they chose to not share their cancer experience with peers at home because they did not want the relationship to become uncomfortable or different.

Safe Space

At camp, ACS feel fully comfortable with their identities as survivors (n = 12). Rather than choosing to dissociate themselves from their cancer experience, ACS who attend camp feel this space is a time to be expressive about their survivorship identity, and they are comfortable sharing their joys and hardships with other campers, volunteers, and counselors. At camp, they know they will not be judged in the same way they might be outside of camp. A younger participant, Max (13 years old), shared his struggle with bullying at school, as he stated, "I get bullied at school cuz they call me germ freak...they say that stuff to me, and like there's a gang of boys who will say, like you are really stupid, and sometimes they'll mimic me." Throughout Max's interview, he expressed his struggles with peers at school and their desire to pick on him because of his differences. Thus, this adolescent found camp to be a place where he was comfortable in his own skin and surrounded by supportive peers who were okay with his differences, which was not something he experienced much in his daily life.

A few campers (n = 3) chose to not share their childhood cancer experience with peers at home. At camp, the survivorship struggles in their daily life are understandable and common; most likely another person at camp had a similar experience. These interactions with peers at camp provided ACS with opportunities to be comfortable in their identity, rather than shying away from the topic or a conversation because they were not sure what the response would be from their peers. Altogether, the majority of ACS in this study perceived camp as a safe space for social interactions, emotional expression, and engaging in the survivor identity.

Peer Survivors

Although ACS only had an opportunity to interact with other ACS once a year at camp, it was evident that the interactions were extremely meaningful. Almost all ACS (n=13) reported that the relationships they created with peer survivors were a main reason they return to camp after transitioning into survivorship. An older adolescent, Jake (17 year old), shared,

I've got friends here...you can always feel like you can say whatever you want. They don't, they understand everything cuz we've all been through it, they all know what it was like. Some people at home, they don't understand the hard part of it. They just think, "Oh you got treatment and now you're better." They don't understand the stuff that goes on afterwards.

Jake spoke about the uniqueness of his friendships at camp and how important these friends at camp are to him because they are different than his friends at home. Many other campers looked forward to spending time with the ACS they had become friends with in previous years, and a few expressed looking forward to making new friends every year they attended. Thus, the camp context served as an environment where ACS could maintain their friendships, in addition to spending time together and simply having fun. These relationships among campers appeared to be easy-going, encouraging, and playful. Furthermore, these camper relationships seemed to form quickly with both individuals becoming instant friends because they were both attending the camp. When asked about these camper relationships, all of the campers attributed this instant friendship to the idea that both had experienced cancer. For instance, when asked a question about the camp environment, Kevin (15 years old) responded,

Like the first time that I came I was kind of nervous about coming and didn't know what to expect and after you come here and see that everybody is here for each other you go home feeling more confident and not really worrying about it...it's great, there's so many friends.

¹ Names of the campers have been changed to maintain anonymity.

These quickly formed relationships also appeared to be automatically viewed as a source of support because the new friend understood the camper on a deeper level than other peers outside of camp. Furthermore, for Kevin, this quick creation of a friendship influenced his self-concept. He specifically stated that the ease of social interactions and creation of friendships helped him to feel more confident in himself and ability to meet new people.

Survivorship mentoring. Although ACS appeared to refer to peer survivors as they spoke about their camp experience, observations throughout the week brought to light the interactions and relationships formed between ACS and younger campers. During the first day of camp, ACS campers engaged with younger campers while participating in various unstructured activities. ACS assisted younger campers in activities that they had learned at camp in previous years, such as creating a bracelet or helping younger campers learn how to play games that were popular at camp. Both male and female ACS appeared to enjoy sharing their knowledge and making sure the younger camper learned new skills. Even if younger campers had physical or medical limitations that made the activity more difficult, ACS campers incorporated them in their activity and helped in any way that they could. Throughout the week, these campers with physical or medical limitations were rarely left alone and had another peer or other-aged camper interacting with them or simply sitting next to them.

Normalization

Out of all camps to attend, ACS chose to be at one that was focused on "having fun" while surrounded by other campers who have experienced cancer. Rather than attending a camp that enables ACS to be surrounded by peers with all backgrounds, it is evident they cherish the time that they have with other cancer survivors, contributing to an environment that normalized the campers' life experiences (i.e., cancer survivorship).

Although the main focus at this camp is "having fun," there were several events that incorporated normalizing and supportive techniques specific for children experiencing cancer and survivorship. For example, a hair-cutting event took place where all campers had an opportunity to donate their hair to wigs made for children who had lost their hair due to cancer treatment. Another supportive event that would only be included at a camp specifically for children who experienced cancer was "Wish Night." This event is held on the last night of camp, and many campers spoke about the importance of this evening to them. At this event, campers have an opportunity to share their cancer journey. It is a time for campers to share their lived experience and the grief surrounding the friends they have lost to cancer.

Self-Esteem Development

During the camp week, it was evident that all ACS were encouraged to participate in all activities and to successfully complete them. Throughout the week, camp staff and campers constantly provided encouragement to other

campers in all different types of activities or just in conversation. The more challenging activities, such as zip-lining or rock wall climbing, typically evoked more encouraging words and gestures. Furthermore, the more difficult activities appeared to be a symbolic experience for some ACS. One camper provided an analogy of this experience in relation to completing cancer treatment and now being in remission. Drew (17 years old) shared,

Sometimes when you're in treatment there's like a, at first you have a tough time getting up to speed and being ready and then when you are busy climbing up that's like the point of like you're making progress and then when you get stuck on that part that's like...what's happening part, but then you finally find that opportunity, when you find that advance that one way to climb up that then you make your way up. In making progress in treatment and then you finally make it...you get more and more stronger and braver as you get through it...once you hit the top you're done with, you have succeeded your journey.

Following completion of these activities, the researcher observed ACS displaying a sense of accomplishment and pride, while prior to the activity they exhibited scared and nervous behaviors. Campers (n = 7) spoke about their increased self-confidence following their time at camp. Of these campers, two were younger ACS who specifically used the word "confidence" in explaining their reason for continuing to attend this camp. An older camper spoke about her belief that other campers should attend because it will help them to feel like they fit in, which in turn may impact their self-confidence. Stephanie (19 years old) stated,

It's a great place for kids that feel like maybe people don't care about them and if they come here I can about guarantee they are going to figure out that there are people that care and there's people like you, you'll fit right in.

The inclusiveness of the camp environment facilitated the feeling of "fitting in," and this, in turn, can influence ACS' self-esteem.

Additionally, the ease of social interactions with old friendships and the creation of newer friendships can influence the ACS' feelings of self-confidence. For example, one ACS shared that she was afraid to start conversations with people she did not know at school and did not have many friends outside of camp. However, in the camp context, her ability to form new friendships reminded her that she is able to make new friends and these interactions were an encouragement for her to try and make more friends when she went home.

Home Experience Versus Camp Experience

Although most of the interviews revolved around the camp experience, more than half of the ACS (n = 9) brought up different aspects of their home life. The ACS expressed feelings about their home life experiences and why this was related to reasons they chose to attend camp each year.

Sibling jealousy. Three campers discussed sibling jealousy. For example, one camper addressed issues with sibling jealousy during her cancer treatment and in survivorship. She expressed difficulty in her relationships with siblings because they felt that she received special treatment because of her cancer experience. As she shared this information, it was evident that this topic was troubling to her. Megan (14 years old) shared,

Like my brother makes a big deal because he thinks I'm spoiled. And I don't know why, but like my dad was with me most of the time but he tries to make it sound like my mom and dad weren't there at all, and weren't there for my brothers or sisters, and that's how he likes to make me feel...I get a little bit more respect [at camp] than I would at home.

This ACS felt that her brother's jealousy had stemmed from when she was actively receiving treatment. Thus, camp was a space for Megan to not feel guilty about her past and to receive support from other peers who may be going through the same experience. In addition, she shared that she enjoys camp because the relationships are easy going and fun-focused.

Non-survivor peer relationship difficulties. Some ACS (n = 5) spoke about experiences that reflected their difficulty with peer relationships outside of camp. Two male ACS reported being bullied at school or treated poorly. For one of these ACS, this appeared to be directly related to their childhood cancer diagnosis and the physical changes that occurred during treatment. Joey (12) stated, "When I was going through my chemo they [campers] never made fun of me or were mean to me, they were supportive. Some of them even cut their hair to be bald like me. So I knew they cared." These ACS appreciated being at camp so that they would not be made fun of by others and would rather experience supportive interactions by peers who they felt were friends. Additionally, a female ACS expressed difficulty forming friendships because she was afraid to try and make new friends. Another female ACS expressed difficulty forming deep friendships because she did not want to tell her childhood cancer experience. Thus, the automatic acceptance, similar cancer experience, and support that occurs within the peer interactions at camp were highly valued by the ACS that struggled with friendships outside of camp.

Discussion

The findings from this study provide further insight and understanding into ACS' social experiences at a week-long oncology camp. It is evident that the ACS viewed the camp environment as a safe space to engage in an identity that they strongly connected to—a cancer survivor. This camp context included valuable social experiences for these ACS, such as building and maintaining relationships. These relationships were particularly meaningful because they were with other individuals who had survived cancer, and ACS seemed to perceive an automatic deeper understanding with one another.

In adolescence, identity formation is a critical developmental task (Steinberg et al., 2011). For the ACS in this study, as evidenced in the cancer survivor identity theme, it was clear that they embraced the cancer survivor identity while in the camp context. Most ACS reported difficulty expressing their cancer survivor identity with friends at home; therefore, they chose not to disclose or discuss their childhood cancer journey with them.

It was clear some ACS were experiencing difficulty navigating their cancer survivor role. This finding is consistent with other literature that has brought to light the difficulty that ACS have expressing their cancer survivor identity (Cantrell & Conte, 2009). Cantrell & Conte (2009) identified an identity paradox for ACS as they strive for normalcy, while establishing and accepting the identity of a cancer survivor. This identity paradox was recognized in campers' interviews, with many ACS reporting that camp was an environment where they could feel and act like normal kids, while still choosing to be at an oncology camp surrounded by other children who are in treatment or survivorship. Thus, camp offered a unique setting to work through the identity paradox, as this environment supports normalcy for childhood cancer survivors. The idea that camp allows for ACS to feel normal was a reason they first attended and a reason as to why they continued to attend camp in survivorship. Apart from camp, ACS appeared to shift towards the identity of a typical adolescent, with some ACS choosing to not share past cancer experiences with friends, as they felt that sharing this information may negatively impact or change friendships at home.

In alignment with the symbolic interactionist perspective, the meaning that ACS perceived from their social experience at camp context was supportive and, in turn, influenced their behaviors. Our findings support other camp literature, as many ACS reported feeling supported by other campers simply because they both had experienced cancer (Bluebond-Langner et al., 1991). Furthermore, some ACS attended camp because of the supportive interactions they experienced. In this context, they did not have to worry about being bullied, sibling jealousy, or being different from their peers. Rather, in this setting they felt normal, could receive support about their struggles at home, and felt comfortable being themselves. In turn, these positive social experiences appeared to influence ACS' social and emotional well-being in the camp context. The observations of ACS at camp were in alignment with findings from two prominent literature reviews on camp research (Martiniuk, 2003; Martiniuk et al., 2014); ACS were observed primarily exhibiting positive behaviors as they were predominantly cheerful, exhibiting enjoyment in activities, and very interactive throughout their week-long camp stay. Very rarely were ACS observed exhibiting anger, sadness, or negative behaviors.

Adolescent cancer survivors also provided insight into their *role* as a camper. As a camper, they are in this environment to not only have fun, but also be a supportive friend to other campers. Although at this camp most conversations were playful and unrelated to the cancer experience, it was also evident that more serious conversations

could happen if a camper initiated the topic. This brings to light the complexity of the role of camper for ASC. This role can encompass the cancer survivor identity, supportive and caring peer, playful friend, and mentor. These unique camper experiences provide support for literature that has recognized the camp context as a place that encourages the growth of several developmental factors, such as: peer relationship building, exploring emerging identities and interests, building character, skills, and emotional regulation (Bialeschki et al., 2007; Martiniuk et al., 2014). Some ACS also mentioned interest in becoming camp counselors the following year in order to continue being able to attend camp because they couldn't envision themselves not attending camp after they have aged out. Thus, for some ACS, their role as a camper is one that they do not want to end, and the next best alternative would be to continue attending camp but in a different role as a counselor.

Limitations

Limitations from this study point to opportunities for future research. For example, by probing further about different topics that appeared to be important to the ACS, the results could have had greater depth and the potential for other ideas may have surfaced. For instance, a second round of interviews could have been completed with ACS in order for the researcher to expand upon the information collected in the first round of interviews. Additionally, making use of follow-up interviews after camp could enable the ACS to reflect on the initial questions in the interview and be able to potentially expand in greater depth on questions when asked a second time.

Additionally, this study was conducted in one camp context, which led to a sample that is not racially or culturally diverse. This lack in diversity within the sample and in the camp context should be considered in future studies. It is important to consider if this homogenous sample is the result of a broader issue, such as ACS who identify non-White not being provided information about supportive community survivorship programming (i.e., camp).

Furthermore, the data collection and analytical processes may have skewed the data. The campers who participated in the interviews were identified by camp counselors, and this may have impacted the data. Lastly, this study may have benefited from another outside auditor in order to validate the themes from the data. A third auditors' perspective could have uncovered more variances in the data or provided a different interpretation of the findings.

In spite of these limitations, this study sheds light on ACS' experiences at an oncology camp and the importance of the social phenomena that occur within this context. It is evident that the social experiences within the camp con-

text are highly valued and meaningful for several different reasons unique to each ACS.

Future Implications

The findings from this study bring to light the many benefits of attending an oncology camp and the reasons as to why ACS continue to attend this type of camp each summer. As ACS transitioned into survivorship, the camp context became a space where they could interact with other ACS, share their possible survivorship struggles (i.e., friendships with peers who did not experience cancer and sibling jealousy), be a mentor for younger campers, feel comfortable in their identity as a survivor, and ultimately continue to participate in activities and social interactions that facilitate positive developmental outcomes.

These psychosocial needs that surface in survivorship are important for child life professionals to consider. As child life professionals are typically involved in a child's psychosocial care during cancer treatment, they have the ability to refer children and families to nearby pediatric camps. This may be especially advantageous for children who child life professionals assess as lacking supportive interactions in their daily lives or who are struggling in their new role as a cancer patient or survivor. Additionally, child life professionals can be involved in mitigating the racial and cultural homoegenity within the camp context. This can be done by ensuring that camp referrals are provided to all pediatric cancer patients and survivors.

Furthermore, this study sheds light on ACS' continued desire to engage in psychosocial opportunities with other survivors, in addition to perhaps being unaware of other community experiences that allow them to continue receiving support by this sub-group. Thus, it is important that ACS who are no longer able to attend camp because they are over 18 years of age be provided with resources specifically focused on social opportunities to interact with peer survivors.

Conclusion

Adolescent cancer survivors' lived social experiences at an oncology camp are a primary reason as to why camp is so important to them. The social interactions within the camp context with peers, counselors, and younger campers are meaningful and impactful. Although each ACS has unique reasons as to why they continue to attend camp each year, it is evident that the camp context encompasses a wide variety of experiences that fulfill their supportive needs and desires in survivorship.

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References

- American Cancer Society. (2018). *Facts & figures*. https://www.cancer.org/cancer/cancer-in-children/key-statistics.html
- American Childhood Cancer Organization. (n.d.). *US* childhood cancer statistics. https://www.acco.org/us-childhood-cancer-statistics/
- Bialeschki, M. D., Henderson, K. A., & James, P. A. (2007). Camp experiences and developmental outcomes for youth. *Child and Adolescent Psychiatric Clinics of North America*, *16*(4), 769–788. https://doi.org/10.1016/j.chc.2007.05.011
- Bluebond-Langner, M., Perkel, D., & Goertzel, T. (1991). Pediatric cancer patients' peer relationships: The impact of an oncology camp experience. *Journal of Psychosocial Oncology*, *9*(2), 67–80. https://doi.org/10.1300/j077v09n02.05
- Brown, B. B. (2004). *Handbook of Adolescent Psychology*. Wiley.
- Brown, R. T., Madan-Swain, A., & Lambert, R. (2003). Posttraumatic stress symptoms in adolescent cancer survivors of childhood cancer and their mothers. *Journal of Traumatic Stress*, *16*(4), 309–318. https://doi.org/10.1023/A:102446541562
- Cantrell, M. A., & Conte, T. M. (2009). Between being cured and being healed: The paradox of childhood cancer survivorship. *Qualitative Health Research*, 19(3), 312–322. https://doi.org/10.1177/1049732308330467
- Cantrell, M. A., & Lupinacci, P. (2008). Investigating the determinants of health-related quality of life among childhood cancer survivors. *Journal of Advanced Nursing*, *64*(1), 73–83. https://doi.org/10.1111/j.1365-2648.2008.04760.x
- COCA-I Brochure. (2014). In Children's Oncology Camping Association, International. https://www.cocai.org/index.php?option=com_content&view=article&id=49 &Itemid=206
- Conrad, A. L., & Altmaier, E. M. (2009). Specialized summer camp for children with cancer: Social support and adjustment. *Journal of Pediatric Oncology Nursing*, *26*(3), 150–157. https://doi.org/10.1177/1043454209334418
- Decker, C. L. (2007). Social support and adolescent cancer survivors: A review of the literature. *Psycho-Oncology*, *16*(1), 1–11. https://doi.org/10.1002/pon.1073
- Deverensky, J. L., Tsanos, A. P., & Handman, M. (1998). Children with cancer: An examination of their coping and adaptive behavior. *Journal of Psychosocial Oncology*, *16*(1), 37–61. https://doi.org/10.1300/j077v16n01_03
- Dunsmore, J., & Quine, S. (1995). Information, support, and decision-making needs and preferences of adolescents with cancer: Implications for health professionals. *Journal of Psychosocial Oncology*, *13*(4), 39–56. https://doi.org/10.1300/j077v13n04_03

- Gillard, A., & Watts, C. E. (2015). Program features and developmental experiences at a camp for youth with cancer. *Children and Youth Services Review*, *35*(1), 890–898. https://doi.org/10.1016/j.childyouth.2013.02.017
- Haluska, H. B., Jessee, P. O., & Nagy, C. M. (2002). Sources of social support: Adolescents with cancer. *Oncology Nursing Forum*, *29*(9), 1317–1324. https://doi.org/10.1188/02.onf.1317-1324
- Ingoldsby, B. B., Smith, S. R., & Miller, J. E. (2004). *Exploring family theories*. Roxbury Publishing Company.
- Jones, B. L., Parker-Raley, J., & Barczyk, A. (2011). Adolescent cancer survivors: Identity paradox and the need to belong. *Qualitative Research Journal*, 21(8), 1033–1040. https://doi.org/10.1177/1049732311404029
- Martiniuk, A. (2003). Camping programs for children with cancer and their families. *Support Care Cancer*, *11*(7), 49–57. https://doi.org/10.1002/pbc.24912
- Martiniuk, A., Silva, M., Amylon, M., & Barr, R. (2014). Camp programs for children with cancer and their families: Review of research progress over the past decade. *Pediatric Blood & Cancer*, *61*(5), 778–787. https://doi.org/10.1002/pbc.24912
- National Cancer Institute. (2018). *Cancer in children and adolescents*. https://www.cancer.gov/types/childhood-cancers/child-adolescent-cancers-fact-sheet
- Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *Psychological Journal*, 20(1), 7–14. https://doi.org/10.14691/cppj.20.1.7
- Ritchie, M. A. (2001). Sources of emotional support for adolescents with cancer. *Journal of Pediatric Oncology Nursing*, *18*(3), 105–110. https://doi.org/10.1053/jpon.2001.23600
- Smith, J. A., & Osborn, M. (2007). *Interpretative Phenomenological Analysis*. Sage Publishing.
- Starks, H., & Trinidad, S. B. (2007). Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Research Journal*, *17*(10), 1372–1380. https://doi.org/10.1177/1049732307307031
- Steinberg, L. (2014). *Adolescence*. Mcgraw-Hill Publishing Company.
- Steinberg, L., Bornstein, M. H., Vandell, D. L., & Rook, K. S. (2011). *Lifespan development: Infancy through emerging adulthood*. McGraw-Hill Publishing Company.
- Stryker, S. (1968). Identity salience and role performance: The relevance of symbolic interaction theory for family research. *Journal of Marriage and the Family*, *30*(55), 58–64. https://doi.org/10.2307/349494

- Török, S., Kökönyei, G., Károlyi, L., Ittzés, A., & Tomcsányi, T. (2006). Outcome effectiveness of therapeutic recreation camping program for adolescents living with cancer and diabetes. *Journal of Adolescent Health*, *39*(3), 445–447. https://doi.org/10.1016/j.jadohealth.2005.12.018
- Wertz, F. J. (2005). Phenomenological research methods for counseling psychology. *Journal of Counseling Psychology*, *52*(2), 167–177. https://doi.org/10.1037/0022-0167.52.2.167
- Wu, Y. P., Prout, K., Roberts, M. C., Parikshak, S., & Amylon, M. D. (2011). Assessing experiences of children who attended a camp for children with cancer and their siblings: A preliminary study. *Child Youth Care Forum*, 40, 121–133. https://doi.org/10.1007/s10566-010-91