



Camp experiences in the lives of adolescents with serious illnesses



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ABSTRACT

This study explored the experiences of a summer camp for adolescents with serious illnesses and included interview responses from campers with different types of serious illnesses. Twenty-four youth aged 14–15 with cancer, sickle cell disease, HIV/AIDS, or metabolic diseases provided videotaped interviews that were analyzed using an interpretative phenomenological approach, and frequencies of responses per theme and diagnosis were computed. Camp experiences varied across diagnostic groups and featured: a sense of belonging, enjoyment, being myself, positive affect, camp programming, adult staff, personal growth, and escape. Some qualitative variations existed between diagnosis groups. Campers with cancer perceived camp as a place for sense of belonging, personal growth, and escape. Campers with HIV/AIDS perceived camp as an opportunity for a sense of belonging, being myself, camp programming, and escape. Campers with sickle cell disease perceived camp as a place for enjoyment, adult staff, being myself, personal growth, and escape. Campers with metabolic diseases perceived camp as a place for personal growth and positive affect. Professionals caring for youth with serious illnesses should consider adding camp to the list of interventions to promote children's well-being. Future research should include more youth and illness types.

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1. Introduction

Summer camps have served as psychosocial interventions for children and adolescents since the earliest days of the organized camp movement in the 1860s (Ramsing, 2007). Nearly concurrent with the beginning of the institution of summer camp, medical specialty camps were specifically created to promote outdoor and social experiences for youth living with serious illnesses and disabilities. Professionals involved in the operation of medical camps structure these camps so that youth with serious illnesses or disabilities can have a place to “just be a kid,” which involves making new friends and engaging in fun activities while being medically supported. Because youth living with serious illness often face isolation and restrictions, have trouble integrating the effects of their disease into their lives, and have difficulty achieving developmental milestones (Pinquart, 2014), medical specialty camps can provide new and normalizing experiences.

Research on medical specialty camps is relevant to the field of children and youth services because these camps are a feature of many pediatric patients' adjunct treatments, yet outcomes have not been compared for participants with different serious illnesses. The psychosocial aspects of camp have been well-studied in children's health care (e.g., Karlson et al., 2013; Knapp, Devine, Dawson, & Piatt, 2015;

Pierre, 2013), but few studies have investigated qualitative differences in responses related to illness type. Scholars and practitioners in the field of children and youth services can use this information to make informed decisions about recommendations to youth and families about the potential benefits of camp experiences. The purpose of this study was to (1) explore the experiences of a summer camp for adolescents with serious illnesses and (2) highlight the differences in interview responses among campers with different types of serious illnesses. The four illness types in this study included cancer, sickle cell disease, HIV/AIDS, and metabolic diseases.

1.1. Cancer

Health-related quality of life issues related to cancer include psychosocial function, importance of peers, experience of healthcare, importance of support, impact of symptoms, striving for normalcy, impact of diagnosis, positive experiences, and financial consequences (Taylor, Pearce, Gibson, Fern, & Whelan, 2013). For adolescents and young adults, psychosocial support is necessary for general health, sexual health, mental health, health behaviors, and transition to survivorship and adulthood (Szalda, Kim, & Ginsberg, 2014). Camps for children with cancer have received a great deal of research attention, and has demonstrated positive impacts of camp on cancer knowledge, mood, self-concept, empathy, friendship, quality of life, sense of belonging,

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and emotional well-being (e.g., Gillard & Watts, 2013; Laing & Moules, 2014; Martiniuk, Silva, Amylon, & Barr, 2014).

1.2. HIV/AIDS

Less well-researched than camps for youth with cancer are camps for youth with HIV/AIDS. Medical issues facing youth with HIV/AIDS include adherence to treatment and linkage to care (Martinez & Chakraborty, 2014). Psychosocial aspects of HIV/AIDS include lack of future orientation, inadequate educational attainment and limited health literacy, failure to focus on the long-term consequences of short-term risk behaviors, and coping ability (Martinez & Chakraborty, 2014). Youth with HIV/AIDS experience more emotional, behavioral, and psychiatric issues than the general youth population and other high-risk groups (Mellins & Malee, 2013). Research on a camp for youth with HIV/AIDS found that the camp supported caring connections, feelings of reprieve and recreation, and increases in knowledge, attitudes, and skills (Gillard, Witt, & Watts, 2011). Other descriptive case studies of camps for youth with HIV/AIDS have shared information on HIV-specific issues about camper recruitment, medical care, and social support (e.g., Pearson & Johnson, 1997; Swartz, 2009).

1.3. Sickle cell disease

Medical issues for youth with sickle cell disease involve managing chronic and acute pain, cerebro-vascular events, and neurocognitive difficulties (Helps, Fuggle, Udwin, & Dick, 2003). A hallmark of sickle cell disease is recurrent, acute, and chronic pain that often requires emergency management and hospitalization (Benton, Ifeagwu, & Smith-Whitely, 2007). Adjustment problems including poor self-concept, social adjustment problems, behavior problems, and symptoms of depression, anxiety, and pica are common and increase with age (Benton, Ifeagwu, & Smith-Whitely, 2007). As with camps for youth with HIV/AIDS, limited research exists on camps for youth with sickle cell disease. In one study that included campers with sickle cell disease with campers with other serious illnesses, hope and goal-directed behaviors contributed to psychosocial functioning following a camp experience (Pierre, 2013). Powars and Brown's (1990) case description provided suggestions of medical support and programming for youth with sickle cell disease at a remote and physically challenging camp site.

1.4. Metabolic diseases

Metabolic diseases can be associated with developmental delay, seizures, and motor function abnormalities (Pierre, 2013). Children with metabolic diseases typically follow life-long demanding and restrictive diets, and additional stressors arise when children make social comparisons and fear stigma because of their illnesses (Sansom-Daly, Peate, Wakefield, Bryant, & Cohn, 2012). Children's daily activities are also affected by frequent hospital visits. Both hospital visits and restrictive diets can increase children's dependence on parents and caregivers and decrease social participation. As with HIV/AIDS and sickle cell disease, very few studies exist on camps for youth with inherited metabolic and mitochondrial diseases. At a camp for girls with phenylketonuria (PKU), short-term outcomes included reductions in dietary phenylalanine intake, plasma phenylalanine levels, and perceived isolation, but the effects returned to baseline within a year (Singh & Kable, 2000). Another study of girls with PKU also found that after camp, campers' phenylalanine levels decreased and nearly all campers stayed in touch, but attitudes about treatment and perceptions of ability to cope with PKU did not significantly change (Waisbren et al., 1997).

1.5. Study purpose

Reviewing research about these four serious illness groups reveals that the type of illness and related psychosocial issues and social

contexts likely has bearing on young people's experiences with positive youth development settings. The camp experience likely differs for adolescent campers based on their medical diagnoses because of particular psychosocial factors influencing the serious illness experience. For example, camp might be a source of refuge for adolescents who have stigmatizing illnesses, but perhaps this is less important for adolescents with illnesses that are less fraught with misinformation and fear. The age group of adolescents for this study was chosen because they were developmentally capable of thinking about hypothetical scenarios and processing abstract thoughts. In this study, we aimed to explore the experiences of camp for adolescents with four different types of serious illness to see if there were qualitative differences in their interview responses, and to see if the potential differences could be connected to the psychosocial and medical aspects of each illness. Findings can inform camp programming and staff training, camp-based medical care, recruitment of campers, and reporting to stakeholders on the camp experience.

1.6. Theoretical framework

This study used Lerner's developmental systems theory (DST) as its guiding framework (Lerner, Almerigi, Theokas, & Lerner, 2005; Lerner & Steinberg, 2004). The theory focuses on the changing relations between developing youth and their changing ecological contexts, and acknowledges that youth are embedded in a larger social context (Lerner & Castellino, 2002). In a camp setting, the context created by counselors and others has bearing on campers' developmental progression, and in turn, campers' development helps shape the camp context. Further, illness-specific social factors in the mesosystem influence camps' policies and procedures regarding recruitment, programming, and staff training. One key element of DST is "fit": activities and experiences that are developmentally appropriate, interesting, and engaging, and that provide developmental support via interactions with caring people and opportunities for building skills. In this study and in this camp, it was important to view both camp and campers' social contexts as settings that could promote or thwart positive development through the camp experience.

2. Methods

2.1. Setting

Founded by actor Paul Newman in 1988, The Hole in the Wall Gang Camp (THITWGC) is a medical specialty camp in Connecticut dedicated to providing "a different kind of healing" to children with serious illnesses and their families throughout the Northeast, free of charge. Each summer, overnight camp sessions run for seven days for youth aged 7–15. THITWGC offers traditional camp activities such as arts and crafts, fishing, talent shows, and campfires, but no specific medical or psychosocial educational activities are conducted. While some campers attended sessions mostly for youth with a particular illness such as immune system disorders or sickle cell disease, other campers attended sessions that mixed youth with different illnesses. Campers were not necessarily aware that they were at a camp with others with the same (or different) illnesses because of the camp's philosophy to be a "hide-away" from the stresses of life for children.

In 2014, THITWGC served children living with cancer, HIV/AIDS, sickle cell disease, metabolic diseases, or other serious illnesses. Pediatric cancers seen at THITWGC included leukemias and brain cancers, along with other types of cancer, accounting for about one-third of campers' diagnoses. Children with HIV/AIDS have attended THITWGC since 1990, and accounted for about 10% of campers. About one-third of THITWGC campers had sickle cell disease. Metabolic diseases included pyruvate kinase deficiency, mitochondrial disease, fatty acid oxidation disorder, methylmalonic acidemia, and tyrosinemia, which accounted for less than 10% of campers' diagnoses. These four groups

comprise the majority of serious illnesses at THITWGC. Campers with illnesses other than the four main groups were excluded from the study.

2.2. Procedure

The Institutional Review Board at Indiana University approved this study. Before the summer of 2014, THITWGC mailed a letter about the study and consent forms to the parents and caregivers of campers aged 14 or 15 who had previously attended this camp and who were enrolled in one of five summer sessions ($N = 105$). Follow-up email reminders were sent to parents/caregivers who had provided email addresses in the THITWGC's database ($n = 60$). Twenty-six parents/caregivers who agreed for their children to be in the study returned completed forms with their other camp paperwork by mail or while dropping off their children on the first day of camp. THITWGC made a list of campers with consent and gave the list to the videographer (a seasonal camp employee).

The first author instructed the videographer on interviewing methods and techniques, such as consistency in wording and probes. The videographer was involved because THITWGC offered an activity in which "senior campers" (i.e., the oldest campers who were aged 14 or 15) were to be individually interviewed on video for "senior documentaries" that would be edited and shown to campers and staff on the last night of camp. The senior documentaries program activity was a long-standing tradition at camp that provided an ideal context in which to gather data for this study. Before the senior documentaries activity, the videographer explained to the campers the purpose of the activity and of the study.

Twenty-four campers with parent and caregiver consent assented to the study and two did not assent. This 23% response rate reflected a higher percentage of participants with cancer (44% of 32) than of those with metabolic diseases (18% of 11), sickle cell disease (17% of 29), and HIV/AIDS (9% of 33). The data collected from the individual video interviews were responses to the following questions: "What is your favorite memory from camp?" "What makes camp special?" "What would you take from camp?" "What is the meaning of camp in your life?" and "What advice do you have for younger campers?" These questions were selected to elicit responses central to the research questions. Probes from the videographer further elucidated answers. Interviews lasted 5–10 min.

After completing filming of the senior documentaries for those campers who provided assent, the videographer gave the unedited video files of campers with parent and caregiver consent to the first author for review. The first author reviewed the videos to ensure campers did not identify themselves or others, and numbered and coded the videos with campers' basic demographic information (retrieved from THITWGC's internal database and included age, gender, and primary medical diagnosis). The first author transferred to the second author video files over a zero-knowledge private, encrypted, and password protected network, and supplied the demographic information after the second author's initial analyses.

2.3. Participants

The twenty-four participants in this study included 17 girls and 7 boys, 18 adolescents aged 15 and 6 aged 14 ($m = 15$, $SD = 0.46$). Six campers were African American (25%), one was Asian (4%), and the remaining 17 were Caucasian (71%). Fourteen participants had cancer (58%), 5 sickle cell disease (21%), 3 HIV/AIDS (13%), and 2 metabolic disease (8%).

2.4. Data analysis

Once camp sessions were completed and campers' videos were filmed, they were transcribed verbatim and verified against the original video recordings. The use of videos added a visual component to the

study that allowed for a more nuanced understanding of data provided by campers because the second author observed facial expressions and gestures. Data were analyzed using guidelines based on interpretative phenomenological analysis (Smith, 2007). Interpretative phenomenological analysis aims to explore how an individual makes sense of a particular phenomenon within a given context (Smith, 2007).

The second author read the transcripts several times to identify any possible themes. These themes were based upon recurring patterns of each camper's thoughts, ideas, and feelings. As patterns emerged, various themes became apparent and were subsequently identified. Once the emergent themes were recognized, the first author reread the transcripts and reviewed the identified themes. The two authors initially agreed on 90% of the themes. The authors discussed and deliberated on the emergent themes to ensure suitability within the framework of the study. Occasionally, some codes and themes seemed to overlap, so the authors reviewed specific transcripts and videos to contextualize the codes comprising the themes in question and placed codes so that the themes were conceptually distinct. A few of the codes and themes were revised until both authors reached consensus and endorsed each theme based on the data. The second author conducted a thorough, line-by-line analysis of all camper interview responses and categorized the primary patterns exhibited by each camper according to the endorsed themes. Once themes were established and camper interview responses identified according to those themes, a final reading of the transcripts was conducted to ensure the themes accurately represented the data.

Additionally, frequencies of responses for each theme per serious illness were determined by the number of responses each camper identified during their interview, coding them per theme, and reporting the response rate for all campers of the same serious illness per established theme, see Table 1. Recognizing the small number of participants, we aimed to explore potential trends in the qualitative data by reporting frequencies of interview responses for each illness and theme. Our purpose in this part of data analysis was to highlight differences in densities of themes for each of the four illness groups to perceive trends. Given that little research has been conducted on campers with HIV/AIDS, sickle cell disease, and metabolic diseases, it was appropriate in this pilot study to delve into how often campers with these illnesses mentioned each theme.

3. Results

Data gathered from five different sessions of summer camp at THITWGC were rich in specific details of how camp influenced the lives of the participants in this study. At times, the individual campers' comments reflected a delighted and energetic mood, while at other moments, they were more thoughtful and reflective. The authors identified eight primary themes around which camp experiences could be categorized. These themes were: sense of belonging, enjoyment, be myself, positive affect, camp programming, adult staff, personal growth, and escape. Each of these themes is discussed in detail below and are supported and reinforced by direct quotations from the campers'

Table 1
Themes identified from open coding, and number of codes per response per diagnosis type.

Theme	HIV/AIDS (3 campers)	Sickle cell disease (5 campers)	Cancer (14 campers)	Metabolic diseases (2 campers)
Belonging	5	6	24	3
Enjoyment	3	10	16	3
Be myself	4	7	11	2
Positive affect	0	4	17	3
Camp programming	4	4	15	2
Adult staff	1	8	5	2
Personal growth	0	4	7	1
Escape	1	2	5	0

transcripts. We also discuss differences in interview responses between some serious illness groups (see [Table 1](#)).

3.1. Sense of belonging

Sense of belonging refers to relationships that were cultivated and maintained throughout the camp session. Sense of belonging was the most identified theme, with 21 of the 24 campers commenting. Those 21 campers commented on sense of belonging 38 different times throughout their video recordings. Sense of belonging can be understood as the sensation of being connected and accepted by one's family, friends, and community ([Kitchen, Williams, & Chowhan, 2012](#)). This theme was most prevalent among campers with cancer and HIV/AIDS.

Many of the campers in this study discussed the camp experience in terms of sense of belonging. For example, one camper shared, "what makes camp special is like how random strangers from all over the world can just, like, come together and be like a family for a week." Another camper stated,

Camp to me is special because of the way it brought these people from different parts of the nation together over a common ground which is, like, our illness that we can't really find someone that we have that certain thing, something that big in common ... like, that's just something that – the reason that brought us here is something bigger and it can't like be taken away or changed.

One camper identified her sense of belonging as a meaningful source to help her deal with her problems. She stated,

The meaning of camp to me is – I don't even know where to begin – camp has done so much for my family that it's just amazing. Camp has helped everyone ... and it's really kind of given me a way to like deal with things and I always know that like if I'm going through problems or if I need someone to talk to I can always contact my camp friends and they'll always be there for me.

A camper identified a sense of belonging as one of the driving forces determining what camp means to him. He said,

People are just together. You're never alone... It's affected me a lot because I'm probably one of the only people in my school that has sickle cell so it's like, there's not really any people to like connect with or talk about it with. So when you come here it's just really fun to talk to people about it or just even know that the people around you share the same reactions and altercations about it.

These descriptions of the importance of a sense of belonging that a camper feels with fellow campers provide important insight into what camp meant to these campers.

3.2. Enjoyment

The second most identified theme describing the camp experience was the theme of enjoyment. Enjoyment has been identified as an integral and essential aspect of childhood development and learning ([Xie, Antle, & Motamedi, 2008](#)). These authors described enjoyment as follows: "the basic premise is that an object of enjoyment causes the subject to experience pleasure by causing concurrent beliefs, which satisfy desires concerning the experience itself." This definition emerged in the interview responses of 20 campers who identified enjoyment as a key part of the camp experience. Thirty-three statements were given that addressed this theme of enjoyment. This theme was most prevalent among campers with sickle cell disease.

This theme of enjoyment was exemplified by a camper, who said,

The meaning of camp in my life is just fun. It's just a fun place to go and like, there's a lot of people here that love you and like you can

just come here and have fun. You don't have to worry about anything else but fun.

A camper gave advice to younger campers:

My advice is to take in this fun experience here, take advantage of it, don't let these days pass by and not do like every activity and have no fun. First of all you should always have fun wherever you go, nothing's boring without you. If you could just always be dancing for no reason, do something silly and also try to not to be sad.

In discussing enjoyment, many camper study participants talked about camp being the central focus of their entire year. Some claimed that they looked forward to camp more than anything else. In describing the meaning of camp, one camper stated, "The meaning of camp in my life is everything. It's what I want to do every single summer. I look forward to it every single summer ... So it's really, really fun."

When asked to identify their favorite moment from camp, many camper study participants stated that they "can't pick out just one." Others simply stated that while at camp, "you can just have the best time of your life." Another camper, while describing the meaning of camp and giving advice to younger campers, summed up the feelings of the campers by saying that they should "just enjoy every single moment that you get at camp because it seems like it goes by so quick. But if you enjoy every moment, it makes it last."

It might seem intuitive that summer camp is fun, but these campers' interview responses reveal that not only was enjoyment prevalent at the THITWGC, it was an essential component of the camp experience. The enjoyment experienced on a daily basis is a core concept that highlighted the importance of camp to these camper study participants.

3.3. Be myself

As some camper study participants described, at camp they did not have to be someone else, but could finally be themselves. This theme of "being myself" emerged in 16 of the 24 campers and was mentioned 25 times. This theme was most prevalent among camper study participants with sickle cell disease and HIV/AIDS.

Many camper study participants talked about the ability to be themselves while at camp because no one was judging them. One camper explained,

The meaning of camp in my life is just like recognizing that even though we all have like this special quality of us we can all, like, come together and have fun for a week without worrying about, like, people judging you.

Another camper, speaking about what makes camp special to her, stated,

I think what makes camp special is a lot of people, it's second nature to judge and when you just come here, everybody is in a judge-free zone and you can just be weird and have fun and nobody's there to judge you.

These two campers identified lack of judgment as being a defining characteristic of what camp means to them. The ability to be themselves without fear of ridicule or being ashamed of their serious illness was a powerful influence on many camper study participants. Similarly, one camper replied,

Camp has affected my life in the most positive way possible because no one really where I'm from has any type of illness or anything. But when you come here it's like everyone has something. So, you don't feel like you're out of place.

Similarly, another camper spoke about how being around people who are going through the same experience has helped him realize important things about himself. He stated,

Camp has really affected my life in many ways. I mean, I think the number one way it's affected my life is now I've learned about a bunch of people who have gone through what I've gone through and that they can continue living their life like a normal human being without having to think about all they've been through. And it makes you realize what everyone else is going through and that your life isn't so bad.

Further demonstrating this main theme of being yourself, a camper said,

Camp is special because you can be whoever you wanna be. Like you can come here and be yourself and no one will judge you because everyone is going through their own struggles and problems. So everyone's like really accepting.

To these campers, camp meant the opportunity to be themselves. Freed from society's stigmatizing labels associated with their illnesses, they could be themselves and pursue their own interests and desires. It is this freedom to be themselves that helped shape the camp experience for many of these camper study participants.

3.4. Positive affect

In addition to the opportunity to be themselves, many camper study participants identified the theme of positive affect. In this study, positive affect was defined as the outward manifestation of positive mood or the experience of favorable emotions (Moskowitz, Shmueli-Blumberg, Acree, & Folkman, 2012). Sixteen different campers commented on this theme 24 different times throughout their interviews. This theme was most prevalent among camper study participants with metabolic diseases.

Speaking about the theme of positive affect, one camper said, "I would take from camp the vibe that I get – the vibe of caring and respect and love that is just emanating through everything, through every activity in the cabins and everywhere." Another camper stated, "I think that if I could take anything from camp back home I would take how loving and accepting everybody is here because it's really – I've never encountered anything like it in my life. And it's just amazing." A camper speaking about what she would take away from camp described her meaning of camp in these words: "I think it would be the positive energy that everyone has. Everyone's so cheerful and happy and always so upbeat no matter where we go. And I would love it if everywhere else had more of that."

Most of the camper study participants who commented on this theme of positive affect spoke about their desire to share that with their family and friends. Most campers wished that the sense of positive emotion that they felt while at camp could be with them no matter where they went. One camper in particular addressed this issue by saying,

I would take the atmosphere of it because it just makes me feel really happy and during the school year when I'm kinda down and I don't have a happy place to go to I just look at my camp bracelets and all the memories that I have from the week and it just makes me so happy inside.

Another camper poignantly described the feelings he had as one of his key takeaways from his time at camp. He said,

I would probably take that feeling of like being wanted because I know, like, for some kids when they go to high school or whatever they don't feel as, like, wanted or like people want to be around them. So I'm just, like, try to make others feel wanted and included because, like, with everything that we went through it's not, like, very often that you're included in a lot of stuff.

This camper expressed that "being wanted" and "included" were happy feelings and did not express himself feeling connected to others, which is why this was not coded for "sense of belonging."

Campers expressed feeling a sense of love, respect, happiness, and caring throughout their time at camp. Further, campers strived to take positive feelings from camp home with them.

3.5. Camp programming

Camp programming includes the facilities, programs, and activities that constitute the framework of a traditional week at THITWGC. Sixteen camper study participants commented 25 times about how camp programming influenced their experience. This theme was most prevalent among campers with HIV/AIDS.

The pool was frequently cited as one aspect of camp programming that emerged as a meaningful experience for camper study participants. One camper said that one of the things he wanted to take from camp was "the pool area because that's something that you don't find everywhere. Usually the water's cold and it's not fully forming." Another camp program that affected the camper study participants included the ropes course and zip line. One camper said,

I have to say my favorite memory from camp would probably be climbing the tower. It was an incredible experience. When I got to the top I felt like I accomplished, you know, what I wanted to do. The zip line was probably the best part also.

Not only did major structured camp activities affect the camper study participants, small things made a big difference. One camper stated, "If I could take anything with me from camp I would take the bandanas ... each one represents our [unit cabin]... and I feel like each color represents what we did that session and it's just very special." The color on his bandana helped represent what camp meant to him more so than the ropes course, theater, or dining hall.

Many camper study participants identified the overall idea of camp and its programs as affecting their meaning of camp. Examples include: "What makes camp special is that it's...like a haven;" "It's an amazing place to me and it's my favorite place to be;" and "I think what makes camp special is that there's really no other place like camp ... it's just something that you can't get anywhere else." These campers spoke of camp in holistic terms. They could not identify just one part of camp, because camp was a concept bigger than the sum of its parts. For example, a camper explained what she would take away from camp. She stated,

I'm not really sure what I would take home with me, if I could take anything. I mean definitely the memories of camp. But I think everything here is perfect and I'd just want to leave it here because if I took it home it wouldn't be the same and everything here is just perfect.

3.6. Adult staff

Related to camp programming, the theme of adult staff included the interactions and modeling of the adult staff at THITWGC. Fourteen camper study participants commented 17 different times about the importance the adult staff had on their camp experience. This theme was most prevalent among camper study participants with sickle cell disease.

One camper commented, "What I think makes camp special is all the counselors who make you feel special. They just, like, if you feel homesick they just, um, like they'll sit with you." Another camper stated, "What allows me to be my true self at camp is all the amazing counselors that are here. They help you along the way."

The camper study participants conveyed a sense of love and compassion towards the adult staff, valuing the staff and their interactions with them. One camper summarized this idea in her statement, "What makes camp special would be that the counselors would do anything to make the experience better for the campers. Like if you ask them to do anything, they're happy to do it." The specific interactions that campers had with the camp staff were a feature of the camp experience.

3.7. Personal growth

Many camper study participants experienced several forms of personal growth during their time at camp. Nine campers commented on the theme of personal growth 12 times throughout their individual interview responses. This theme was equally prevalent among campers with sickle cell disease, cancer, and metabolic diseases. Several campers commented on their abilities to grow as people and that they wished and hoped that their growth continued after camp ended. One camper stated,

The love that I received here made me a better person because I was able to have more independence yet still have a lot of fun whenever I want and always find the bright side of things instead of things that are negative and pessimistic. And I like, have more confidence in myself and how I – like every year I do [the talent show] and by doing that it hopefully gives me more confidence in myself to do other things outside of camp.

A camper identified this theme of personal growth as the main take away from camp. He said,

Everything here has made me feel so confident and like I'm able to do anything I want to do. And it just shows me that even though I have challenges that other people might not it doesn't prevent me from doing anything. I can still do anything just as well as someone who's completely healthy.

Additionally, camper study participants perceived an opportunity for personal growth as a positive aspect of their lives. Many campers explained that if they did not have camp in their lives they would not be as happy and optimistic as they are now. For example, one camper stated,

Camp has affected me and made me a better person. I don't think - if it weren't for camp - I don't think I'd be mature. I think I would be a very angry person. So camp really helped me be the person I am.

3.8. Escape

Eight camper study participants spoke about our last identified theme, escape, as a key camp experience. This theme was equally discussed among camper study participants with HIV/AIDS, sickle cell disease, and cancer. All of these campers were dealing with serious medical conditions and many of them enjoyed the ability to get away from “being sick” for a few days. One camper said, “What I think makes camp special is kind of like the isolation from like the outside of the world, like the rest of the world because – it's just like a different atmosphere.” Another camper stated, “The meaning of camp in my life is – it's an escape from the real world and it's just a way to get rid of your problems and your stress and everything like that.” Camp offered these youth the opportunity to get away from the stress of medical treatments, school assignments, doctors' visits, and the constant reminder that they are different from everyone else because they are sick. Those worries were not present at camp. A camper shared,

I think the meaning of camp in my life is camp is pretty much a second home for me. I've learned to remember names of people. The meaning of it is just a little tiny piece of paradise here that I can go and I can just leave my worries behind.

The camp experience of many of these camper study participants was grounded in this theme that when they come to camp, their worries stay home.

4. Discussion

This study explored the camp experience of adolescents with different serious illnesses. Overall, campers shared that camp meant: a sense

of belonging, enjoyment, being myself, positive affect, camp programming, adult staff, personal growth, and escape. Some qualitative variations existed between illness groups. Specifically, campers with cancer perceived camp as a place for sense of belonging, escape, and personal growth. Campers with HIV/AIDS perceived camp as an opportunity for sense of belonging, being myself, camp programming, and escape. Campers with sickle cell disease perceived camp as a place for enjoyment, adult staff, being myself, personal growth, and escape. Campers with metabolic disease perceived camp as a place for personal growth and positive affect. Although there were differences between campers by illness group, it is important to remember that nearly all campers referenced most of the eight themes (see Table 1).

This study adds to the literature on medical specialty camps because campers' perceptions of the camp experience are not well-understood and this study provides additional understanding of this phenomenon. Additionally, to our knowledge, no comparisons between adolescents with various serious illnesses have been conducted to elucidate qualitative differences across illness groups, and this study showed some differences in interview responses for youth with four different medical diagnoses.

Situating this study in developmental systems theory, we see that the social and medical contexts of campers as related to their diagnoses likely influenced their interview responses. Thinking of camp as a system, we see campers in the center of a camp context that provided developmentally-appropriate opportunities given the larger meso-system of health and social contexts. Within the interactions between campers and camp context, we can see elements of positive youth development within the themes found in the data, most notably in the themes of belonging, being myself, and personal growth.

Focusing on specific findings related to the two biggest themes of “being myself” and “sense of belonging,” several potential interpretations exist. First, stigma likely played a role in the interview responses about “being myself” for youth with sickle cell disease and HIV/AIDS. That is, outside of camp, youth with HIV/AIDS often feel constrained from telling others about their illnesses due to stigma about the conditions (Gillard & Roark, 2013). Further, youth with sickle cell typically receive little or no professional counseling or education (Acharya, Lang, & Ross, 2009), nor do they receive any from their communities because of stigma. Yet, at camp, youth could focus on other parts of their identities without the fear of negative appraisals. Second, it was interesting that campers with HIV/AIDS (and cancer) but not sickle cell disease most frequently mentioned camp as a “sense of belonging.” Campers with sickle cell disease seemed to perceive camp mostly in recreational terms (especially themes of enjoyment, adult staff, and escape), which makes sense because their everyday lives typically involve more frequent pain management and acute hospitalizations than campers with other serious illnesses and parent/caregiver restrictions on activities, yet at camp they could engage in fun activities with caring people. Campers with HIV/AIDS were in more robust physical condition than campers with sickle cell disease (Sharon Space, M.D., THITWGC Medical Director, personal communication), which might explain why campers with sickle cell perceived camp as recreational and campers with HIV/AIDS perceived camp more as a community. That is, campers with HIV/AIDS had more of their basic physical needs met and could thus engage in meeting their social needs. Further, awareness about sickle cell disease is low in campers' communities and the media (Jenerette & Brewer, 2010), but awareness (albeit often misinformed) about HIV/AIDS is more prevalent, which might have influenced campers to perceive camp as a place for belonging, as it did for campers with cancer, another disease that receives wide attention. That is, finding a sense of belonging for campers with cancer and HIV/AIDS could be important for these groups because young people with diseases that are often mentioned in their communities and the media might seek similar peers for connection.

4.1. Implications for Practice

The findings suggest several implications for practice. First, children and youth services professionals and others should consider

recommending a medically-supported summer camp to eligible adolescent patients. Adolescents living with serious illness do not typically have many opportunities to engage in a developmentally supportive youth context, and the developmental supports found in medical summer camp can help youth gain a sense of normalcy in personal and social experiences that is otherwise absent. Second, children and youth services professionals can use the findings from this study to tailor their discussions about camp to adolescents with different serious illnesses. Specifically, given that many youth with HIV/AIDS and sickle cell disease are hesitant to share their illnesses with others and thus tend to feel isolated, camp can be offered as an opportunity to experience a place to “be themselves.” For adolescents with cancer and HIV/AIDS, camp can be positioned as a place to belong and an escape from disease-related fears and tribulations. For adolescents with sickle cell disease, the recreational aspects of camp can be emphasized. For adolescents with metabolic diseases, camp can be positioned as offering opportunities for positive affect.

Limitations of this study include issues of generalizability, sample, and methods. As in all qualitative studies, findings from this study apply to these participants in this setting and information cannot be generalized to all medical camps. The small sample consisted mostly of adolescents with cancer, while youth with sickle cell disease, HIV/AIDS, or metabolic disease were fewer in number. The disproportionate sample might have missed additional data from adolescents with non-cancer illnesses, which could have affected findings. Future research should include more participants with illnesses other than cancer for comparison. Finally, the methods used in this study to collect data through videotaped interviews might have constrained participants' interview responses because they could have felt self-conscious about their replies, even though the videographer worked hard to warmly prepare and assure participants. Future research could employ in-depth interviewing without video recording or other methods to see if the same pattern of findings emerges. Including more participants with each illness type (especially serious illnesses other than cancer) would allow for inferential statistics to be conducted while increasing the representation of each illness.

In conclusion, this study found qualitative differences between youth with different serious illnesses in terms of how they perceived the camp experience. Future research should continue to explore the potential of youth contexts such as summer camps to provide different types of developmental support. Medical and social work professionals should continue to promote camp to children in their care as a place to experience a sense of belonging, enjoyment, and opportunities to be themselves. Adults who care for youth with serious illnesses should include camp on the list of interventions to promote children's well-being.

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