



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

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