Outcomes and Processes at a Camp for Youth With HIV/AIDS

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Abstract

The impact of HIV/AIDS on the lives of youth with this chronic illness suggests the need for additional support as youth develop. Summer camp can serve as a therapeutic intervention for youth with HIV/AIDS. Using a case study employing observations, focus groups, and interviews, we examined outcomes associated with participation in a camp for youth with HIV/AIDS, and program processes that influenced outcomes. Findings showed that camp played a major developmental role for youth. Three outcomes of camp emerged: (a) forming caring connections (awareness of commonalities, lack of isolation); (b) feeling reprieve and recreation (fun activities, anticipation of and reflection on camp, sense of freedom); and (c) increasing knowledge, attitudes, and skills (conflict management, disclosure, skill learning and education, medication adherence). Processes included formal and informal education, staff–camper interactions, long-term relationships, outside-of-camp support, activities, planning for camper needs, accessibility, and freedom from worry. We discuss implications for youth programs.

Keywords

adolescents / youth; case studies; children, growth and development; children, illness and disease; focus groups; HIV/AIDS, interviews; observation; psychosocial issues

In 2007, an estimated 14,489 people age 19 and younger were living with HIV or AIDS in the United States, as reported by the 37 states and five U.S. dependent areas with long-term, confidential, name-based HIV infection reporting (Centers for Disease Control and Prevention, 2008). Although these diagnoses reflect increasing numbers of behavioral infections, most young people were perinatally infected (i.e., the virus was passed from mother to child during pregnancy, labor and delivery, or breastfeeding). However, since 1996, perinatal HIV transmissions have decreased to near zero because of advancements in antiretroviral treatments during pregnancy and labor (Rogers, 2006). Additionally, with the advent of highly active antiretroviral treatments, children with HIV/AIDS are surviving well into adulthood (Wiener & Battles, 2006). The aging population of HIV-infected youth suggests a need for managing developmental transitions, such as addressing issues related to intimacy, self-care, and well-being.

Understanding these transitions is complicated by the depth and breadth of issues surrounding HIV/AIDS for young people, creating a need to identify promising practices for treatment and interventions (Orban et al., 2010; Steele, Nelson, & Cole, 2007). One nonclinical therapeutic intervention outside the formal medical setting is summer camp. However, research on camps for youth with HIV/AIDS is sparse. We addressed the lack of literature in this area by studying the developmental potential of camp, especially the outcomes associated with participation in a camp for youth with HIV/AIDS and the program processes that influenced those outcomes.

Literature Review

Youth With HIV/AIDS

Compared to children without HIV, children infected with HIV more frequently experience developmental challenges, such as declines in gross and fine motor skills, mental health issues, and cognitive functioning (such as visual–spatial orientation and language ability), and poor academic achievement (Burns, Hernandez-Reif,

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psychosocial issues particularly affecting young people (Kant, 2010). In a review of literature using a socioecological framework, Burns and colleagues discussed physical symptoms of HIV/AIDS, including neurological abnormalities, prolonged fever, diarrhea, fatigue, pneumonia, and mouth and skin disorders. HIV causes a weakening of the immune system, making people more vulnerable to opportunistic infections and cancers. Burns and colleagues also suggested that the physical effects of HIV/AIDS can become magnified in the high numbers of youth with HIV/AIDS in home environments that include prenatal drug exposure, poverty, violence, and abuse.

In the mid-1990s, a greater understanding of HIV/AIDS led to highly active antiretroviral therapies that reduced mortality and morbidity rates for youth with HIV/AIDS (Merzel, VanDevanter, & Irvine, 2008; Vijayan, Benin, Wagner, Romano, & Andiman, 2009); however, medication adherence is one of the most difficult parts of living with HIV/AIDS (e.g., Garvie, Wilkins, & Young, 2010; Merzel et al.; Orban et al., 2010). Taking medication as prescribed is crucial because the level of HIV virus increases and immune system functioning decreases when strict adherence to the treatment regimen does not occur (Garvie et al.; Vijayan et al.). Adherence to medication regimens is frequently suboptimal for children and adolescents, and consistent with those observed for the adult population (Marhefka et al., 2008; Naar-King et al., 2006; Steele et al., 2007). In a study conducted by Veinot et al. (2006), adolescents reported four themes regarding perceptions of and experiences with antiretroviral treatment: treatment knowledge (confusion and skepticism), treatment decision making (lack of choice and feeling emotionally unprepared), difficulties taking medications (social routine disruption, feeling “different,” and side effects), and inconsistent treatment adherence and treatment interruptions.

Other studies have identified areas of familial involvement that impact adherence, such as parent–child communication about HIV/AIDS, levels and types of disclosure, and stressors (Steele et al., 2007; Wiener, Mellins, Marhefka, & Battles, 2007). Family-related medical issues include self-management of medication, such as adhering to strict schedules, making treatment decisions, planning for transition of care, and interactions with medical personnel. These issues are difficult for all adolescents, but especially for those with HIV/AIDS, who might be hesitant to share personal information with strangers (Mill, Edwards, Jackson, MacLean, & Chaw-Kant, 2010). In a review of literature using a socioecological framework, Steele et al. discussed several psychosocial issues particularly affecting young people with HIV/AIDS, such as behavior, emotions, gender, age, social support availability, coping, and quality-of-life differences. Family issues included bereavement, changes in primary caregivers (and their willingness and ability to provide care to youth), and considerations of familial poverty, violence, and drug use.

These issues are complicated by social ecologies of youth with HIV/AIDS that are often characterized by poverty, difficulty in accessing resources, lack of social support, chaotic family issues (such as parental drug use, illness, and death), and cultural beliefs regarding the disease (Naar-King et al., 2006; Steele et al., 2007). Personal issues within the social ecology include fear related to the loss of parents and caregivers, loss of relationships once status is disclosed, pain from treatments, and resistance to difficult treatment regimens. Individual social factors related to HIV/AIDS include disclosure (both to the youth with HIV/AIDS and to their friends and family) and stigma.

Disclosure is an overarching issue in the lives of youth with HIV/AIDS. Wiener and Lyon (2006) discussed several issues related to the concept of disclosure. First, youth must learn that they have HIV, which can be upsetting if revealed inappropriately. Parents and caregivers often do not tell their children that they have the illness because of shame or a desire to protect them from the potentially negative effects of stigma. Second, youth must decide which family members and friends (if any) to tell. Youth must also make decisions on how to disclose to others with some level of involvement in their health, such as school nurses or sports team coaches. Finally, youth need to learn how to disclose their status to potential romantic partners. Decisions of whether, when, and to whom to disclose their illness is a unique aspect of HIV/AIDS (Steele et al., 2007). This uniqueness arises from the particular stigma associated with HIV/AIDS, and this stigma exists because of perceptions about the medicolegal nature of the illness and, especially, its contagion. However, overcoming the effects of stigma is critical for young people to exercise their right to access to comprehensive health care (de Carvalho Mesquita Ayres et al., 2006).

Some research exists on other psychosocial issues for youth with HIV/AIDS (e.g., Kang, Mellins, Yiu Kee Ng, Robinson, & Abrams, 2008; Marhefka et al., 2009). We identified one study related to a nonclinical, psychosocial intervention for 30 youth aged 2 to 15 who were infected with or affected by HIV/AIDS (Kmita, Baranska, & Niemiec, 2002). The researchers used qualitative methods to investigate the importance of family empowerment in restoring self-efficacy and self-esteem, and in developing positive coping and decision-making processes, and described differences in settings for psychosocial interventions between an outpatient clinic and a therapeutic
family camp. The authors concluded that including non-medical settings in psychosocial interventions seems to be optimal, especially for highly vulnerable families. It was more difficult to motivate families to attend meetings in a medical context, but easier to interact with families in the camp setting. For example, camp group activities (parent and youth support groups, singing, walking) seemed the most effective avenue for both children and caregivers to express themselves and their feelings, and seemed to have lasting influence on participants’ decisions to disclose HIV status to others.

**Summer Camps**

Although many researchers have investigated the experiences of adult populations of people living with HIV/AIDS, especially in this journal (e.g., Bar-Lev, 2008; Baumgartner & David, 2009; Bletzer, 2007), less attention has been paid to nonclinical interventions for young people. Nonclinical settings have been shown to positively influence outcomes for chronic illnesses other than HIV/AIDS, such as camps for youth with cancer (e.g., Meltzer & Rourke, 2005) and diabetes (e.g., Hill & Sibthorp, 2006). Summer camp is one nonclinical setting often used as a therapeutic intervention for youth with disabilities (such as mobility or cognitive impairments) and chronic illness. Typically, camps are designed to foster positive relationships and competence-building opportunities, and offer supports and opportunities for youth to initiate and engage in behaviors that aid in the transition to adulthood.

Although camps aim to provide supports and opportunities for positive youth development for all campers, occasional negative issues arise. A few studies conducted in camp settings revealed that problems such as racism and sexism (Moore, 2001), friendship difficulties (Blachman & Hinshaw, 2002), and aggression (Zalecki & Hinshaw, 2004) can be experienced at camp as well as in other youth settings. Additionally, homesickness is possible at residential programs such as camp, and can cause potentially deleterious effects on youth (Thurber, 2005). However, research on the outcomes of camp participation consistently demonstrates that camp has positive implications for identity development, social skills, physical and thinking skills, and positive values and spirituality (Bialeschki, Henderson, & James, 2007; Henderson, Whitaker, Bialeschki, Scanlin, & Thurber, 2007). A few researchers have explored supports and opportunities within the camp setting, such as autonomy support (Ramsing & Sibthorp, 2008), camp management practices (Henderson, Powell, & Scanlin, 2005), and camp staff factors (such as training and motivation; DeGraaf & Neal, 1993; Henderson et al., 2007). However, more research is needed to better relate camps’ program theories, goals, and program components to outcomes for campers. Researchers have mostly focused on linking participation to outcomes, and paid less attention to what happens within the program that might influence outcomes. Understanding the “black box” (i.e., what happens between inputs and outputs) of program participation and outcomes can inform practice to better optimize outcomes for youth.

Camp has long been an opportunity for youth to become empowered and to build character, skills, and relationships. Recognizing these strengths of camp settings, professionals serving youth with disabilities have advocated that this population stands to greatly benefit from this experience (e.g., Bluebond-Langner, Perkel, & Goertzel, 1991; McAuliffe-Fogarty, Ramsing, & Hill, 2007). Camps serving youth with disabilities attempt to provide them with opportunities that many youth without disabilities experience in their daily lives. Many of these types of camps aim to provide youth with opportunities to develop coping skills, education about their conditions, a sense of belonging, and leisure and recreation activities in an accessible environment (e.g., McAuliffe-Fogarty et al.; Wellisch, Crater, Wiley, Belin, & Weinstein, 2006). A similar concentrated social support resource for youth is found in self-help support groups. Studies demonstrate that these groups support coping with bereavement (McFerran, Roberts, & O’Grady, 2010), peer support for resilience and well-being in adjusting to life with a chronic illness (Olsson, Boyce, Tournbourou, & Sawyer, 2005), and dealing with substance use issues (Kelly, Dow, Yeterian, & Kahler, 2010).

There is an acute need to understand how programs such as camp can support youths’ development, especially youth living with chronic illnesses such as HIV/AIDS, who face additional challenges in their developmental processes beyond those experienced by youth without chronic illness (Britto, 2006; Dodge & Pettit, 2003; Sawyer, Drew, Yeo, & Britto, 2007). Often, researchers seemingly assume developmental processes to be universal to all groups of young people (e.g., Benson, Scales, Hamilton, & Sesma, 2006; Damon, 2004; Larson, 2000; Lerner, Dowling, & Anderson, 2003). Additionally, we need to understand how different youth program contextual factors (e.g., activities and organizational goals) can influence various outcomes for youth throughout their development (Eccles & Gootman, 2002; Mahoney, Larson, & Eccles, 2005; Roth & Brooks-Gunn, 2003). Stakeholders such as program administrators and staff, funding agencies, parents, and youth are interested in learning how processes found within youth program structures and practices can provide young people with opportunities to experience desirable developmental...
outcomes (e.g., Borden & Perkins, 2006; Henderson, Whitaker, et al., 2007; Lerner et al., 2005). Achieving developmental outcomes is often associated with better health (e.g., Roth & Brooks-Gunn, 2003; Youngblade et al., 2007).

More information about how campers with chronic illness perceive the camp context (i.e., camp processes) would help to better meet campers’ needs (Henderson, Bialeschki, & James, 2007). Although some empirical research exists on camps (e.g., Garst & Bruce, 2003; Henderson, Whitaker, et al., 2007; Thurber, Scanlin, Scheuler, & Henderson, 2007), few studies have examined the features of the programmatic contexts or processes of youth development (Anderson-Butcher, Cash, Saltzburg, Midle, & Pace, 2004; Fredricks & Eccles, 2005; Kahne et al., 2001). Understanding how particular programmatic inputs and processes optimize outcomes is a key step in the design and implementation of quality nonclinical and recreation-based programs that support youth development. It is critical to move beyond a focus on the link between the amount of participation and outcomes to a wider view of the processes that can lead to desired developmental outcomes resulting from camp participation by youth with chronic illnesses.

Given the above issues and extant literature, our purpose in this study was to understand the developmental context for youth aged 7 to 19 with HIV/AIDS at a barrier-free camp. Specifically, we sought to answer the following research questions: (a) What were the developmental outcomes experienced by youth as a result of attending camp? and (b) What were the processes that facilitated youth development at camp?

Methods

An interpretive case study framework was used to investigate the research questions (Yin, 2003). Researchers who employ a case study methodology ask “how” or “why” questions about complex social phenomena. The case of interest in this study was a camp for youth with HIV/AIDS. We chose qualitative methods because we sought to understand how the camp experience provided supports and opportunities for development to campers through the exploration of processes and outcomes at this camp. Our study was approved and overseen by the Texas A&M University Institutional Review Board. The camp we studied permitted and provided logistical support for the research efforts for this study. We followed ethical standards for research with youth and vulnerable populations (e.g., Carnevale, Macdonald, Bluebond-Langner, & McKeever, 2008; Trussell, 2008).

Camp Strong, a program of an AIDS foundation in a major southern city, agreed to be the case for this study. Each year, Discover Camp hosts Camp Strong at its barrier-free resident camp (i.e., fully accessible in facility design and program activities to foster camper choice and independence). Discover Camp collaborates with a variety of agencies to provide programming for youth with disabilities and chronic illness. We selected Camp Strong because of our existing association with Discover Camp as program evaluators, the enthusiasm of the Camp Strong director to participate in a study, and because, as noted, research on youth with HIV/AIDS is sparse.

Each year, the local AIDS foundation offers two summer programs for young people living with HIV/AIDS: Camp Strong and Teen Forum. Camp Strong serves 140 to 160 youth aged 6 to 16 for 6 days each July. Approximately 90% of campers are African American, 5% are Hispanic, and 5% are mixed race or White. Most campers are perinatally infected with HIV, and a few are behaviorally infected. All campers aged 12 and older are aware of their HIV status, and some of the younger campers know their status. Approximately 10% of the campers have mobility impairments. Most campers experience chaotic living situations because of poverty, changes in primary caregivers, and lack of resources. Caseworkers or doctors recommend youth to attend camp based on their sufficient health and compliance with treatment and psychosocial goals, and there is no need to prioritize which young people can attend the camp. Additionally, in June of each year, the AIDS foundation offers a 6-day program called Teen Forum for 20 to 30 young people aged 15 to 19 who are too old for camp, yet still in need of support and education. A series of life-skills-driven workshops, and networking with peers and professionals, are aimed to prepare Teen Forum participants to smoothly transition into adulthood while they gain an understanding of the needs and challenges facing adults living with HIV/AIDS.

During their week at camp, campers participate in several recreational activities such as swimming, canoeing, dances, and challenging outdoor personal development and team-building activities. Additionally, campers aged 12 to 16 attend 1- to 2-hour educational workshops called Teen Talk. Trained adults with extensive experience interacting with youth with HIV/AIDS facilitate Teen Talk sessions on most camp nights. Younger campers learn basic facts about HIV and older campers learn about disclosure issues, transmission, and goal setting. During Teen Talk, campers freely discuss issues they have with medication adherence, disclosure, and other HIV-specific topics, and hear from others who face similar situations. See Table 1 for a typical daily schedule.

Procedures

To optimize the potential for saturation, data were collected at three different times. First, we conducted camper
focus groups and staff interviews in 2007 as part of an overall Discover Camp program evaluation that included Camp Strong. Second, we interviewed former Camp Strong campers during their first participant experience at Teen Forum. Third, in 2008 we conducted camper and staff interviews, participant observations, and artifact reviews at Camp Strong. See Table 2 for a summary of data sources.

Purposive sampling procedures guided the selection of participants (Lincoln & Guba, 1985). Participants were approached through caregivers, who provided informed consent prior to the start of camp. When campers arrived at camp, we compiled a list of those whose parents or caregivers had consented to allow them to participate in the study. After consultation with the camp director, lead doctor, and a social worker, we selected campers and staff who reflected a wide variety of attitudes (i.e., different levels of enthusiasm for activities) and experiences (i.e., number of summers spent at Camp Strong). After explaining the study to campers, all campers and staff who were approached provided their assent to participate in the study before participating in interviews. To capture the diversity of campers present at camp, we also selected campers who reflected the overall demographic composition of the camp, as noted earlier.

Interview and focus group questions were semistructured and relied heavily on probes. The purpose of the camper interviews was to explore their memorable camp experiences, the meaning of camp in their lives, relationships with other campers and counselors, comparison of camp to other life experiences, and other feelings about camp. Examples of camper questions included: “Complete this sentence: Camp is a place where I . . . .” “Compare camp to other parts of your daily life. How are they similar to and different from each other?” and “What were the most memorable experiences from camp?” Interviews and focus groups lasted between 20 and 40 minutes.

Camper and former campers aged 14 to 19 were selected for individual interviews because they had more years of experience at camp and the ability to thoughtfully reflect on their experiences and lives, and because youth aged 14 and older are well into the formal operational stage of cognitive development (Piaget, 2000). We conducted interviews with campers aged 14 to 16 during Camp Strong and with former campers aged 16 to 19 at Teen Forum. These two data collection periods encompassed the broadest number of potential interview participants necessary to ensure saturation.

In 2007, we conducted focus groups at Camp Strong with 19 campers aged 7 to 16 as part of a program evaluation, with the purpose of understanding the outcomes of camp participation. The focus group participants included youth aged 7 ($n = 3$), 8 ($n = 1$), 9 ($n = 1$), 10 ($n = 2$), 11 ($n = 3$), 12 ($n = 2$), 13 ($n = 2$), 14 ($n = 2$), 15 ($n = 2$), and 16 ($n = 1$). Focus groups were not conducted with Teen Forum participants in 2007 because the program was still in development.

Counselors, medical staff, psychosocial staff, and the camp director participated in both formal and informal interviews. The purpose of the staff interviews was to elicit information about their perceptions of camper outcomes related to camper participation. Examples of staff interview questions included: “What changes have you observed in campers?” and “What do campers like about their experience here?” Most interviews lasted 10 to 40 minutes, with a few lasting up to 90 minutes.

The first author (Gillard) was a participant observer during Teen Forum and Camp Strong; she served as a mentor and counselor, respectively. As a mentor, she was responsible for driving participants to and supervising participants during activities, and participating in group processing activities. At Camp Strong, she served as an extra counselor for a cabin group of girls aged 13 to 14.

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
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<tbody>
<tr>
<td>7:15-8:00 a.m.</td>
<td>Early morning fishing</td>
</tr>
<tr>
<td>8:00-8:45 a.m.</td>
<td>Breakfast, followed by morning aerobics and Camp News Network announcements</td>
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<tr>
<td>9:00 a.m.-12:00 p.m.</td>
<td>Three activity slots of 45 minutes each. Activities included sports, arts and crafts, biking, canoeing, fishing, challenge course, horseback riding and visiting barnyard animals, drum circle, parachute games, archery, paintball, basketball, softball, kickball, and cooking.</td>
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<tr>
<td>12:00 p.m.-12:45 p.m.</td>
<td>Lunch</td>
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<tr>
<td>1:00-2:30 p.m.</td>
<td>Rest time</td>
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<tr>
<td>2:30-3:00 p.m.</td>
<td>Canteen (snacks, free-play basketball)</td>
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<tr>
<td>3:00-5:30 p.m.</td>
<td>Free swim, plus one or two activities from the morning list, above</td>
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<tr>
<td>5:45-6:45 p.m.</td>
<td>Dinner</td>
</tr>
<tr>
<td>7:00-9:00 p.m.</td>
<td>Evening activity (talent show, games, and so forth)</td>
</tr>
<tr>
<td>9:00-11:00 p.m.</td>
<td>Teen Talk</td>
</tr>
<tr>
<td>12:00 midnight</td>
<td>Lights out</td>
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</table>
when other counselors were on break and at night in the cabin, but had no other responsibilities and was free to conduct research activities as needed. She participated in activities with her assigned cabin group during non-research time. During both Teen Forum and Camp Strong, she recorded field notes during “down” time, and expanded upon them after the programs. Additionally, she conducted artifact review of training manuals, Web sites, camp program supplies, and camp memorabilia, seeking to gain a greater understanding of the processes that fostered supports and opportunities for camper outcomes.

Data Analysis

Data collection, transcription, and analysis occurred iteratively throughout the research process. The data analysis was conducted in two parts, and we employed qualitative data analysis software. First, we coded data from the summer of 2007 and identified themes that related to the purpose of the study. Next, we conducted and transcribed interviews from the summer of 2008. We then analyzed the interviews, unstructured observations, and artifact review data following the analytic induction procedures as outlined by Strauss and Corbin (1998). Analysis using the constant comparison method generated a provisional theory of how camp processes related to outcomes for campers. We compared and contrasted data elicited from campers and staff through interviews, as well as from observations, to establish congruence or incongruence between these different groups and methods, and to see if the processes that influence campers’ perceptions of camp context seemed to be specific or general.

We employed several methods to verify the trustworthiness and reliability of the findings (Creswell, 2003; Yin, 2003). First, we triangulated the examination of campers’ experiences from the different points of view of staff members and campers. Then we compared this with observations from the field. Member checking further refined our themes and consisted of sharing preliminary interpretations with the camp director, one staff member, and a camper, as well as with colleagues with knowledge of camps for youth with chronic illnesses. Last, we identified and examined what appeared to be discrepant findings.

In the field and during data analysis, the first author negotiated several roles throughout camp. She was reflexive of how her experience (especially directing camps) intruded into analyses; specifically, ideas of how camp “should” be run and what camp “should” do for campers. In the field and during data analysis, she mindfully processed emotions of pity, fear, and sadness for the campers facing hardships (Chodron, 1997; Suzuki, 2001). In addition, when judgmental or emotional thoughts emerged, she attempted to return to a focus on answering the research questions and remaining present with the data.

Results

Results were drawn from data collected through 17 one-on-one interviews with campers aged 14 to 19 during summer 2008, one-on-one interviews with 15 staff members conducted over the summers of 2007 and 2008, six

Table 2. Summary of Study Data

<table>
<thead>
<tr>
<th>Data Collection Site</th>
<th>Focus Groups</th>
<th>Individual Camper Interviews</th>
<th>Individual Staff interviews</th>
<th>Observations</th>
</tr>
</thead>
<tbody>
<tr>
<td>July, 2007: Camp Strong</td>
<td>6 focus groups with 19 youth ages 7 to 16</td>
<td>None</td>
<td>1 each with camp director, social worker, and doctor; 4 with counselors</td>
<td>Informal; 10 to 20 minutes in dining hall and activity areas (3 people at 2 activities each)</td>
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<tr>
<td>(Discover Camp)</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>June, 2008: Teen Forum</td>
<td>None</td>
<td>8 interviews with 9 campers (1 interview was with 2 campers)</td>
<td>Unstructured discussions with camp director and comentor</td>
<td>Participant observations in a mentor role, artifact review</td>
</tr>
<tr>
<td>July, 2008: Camp Strong</td>
<td>None</td>
<td>8 interviews</td>
<td>1 formal interview with counselor; 4 informal interviews with counselors; 1 informal interview (each) with doctor and social worker; 1 formal and 1 informal interview with camp director</td>
<td>Participant observations in a counselor role, artifact review, unstructured observations</td>
</tr>
<tr>
<td>Total:</td>
<td>19 campers</td>
<td>17 campers</td>
<td>15 staff</td>
<td>14 days as participant observer</td>
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</table>
focus groups with 19 campers aged 7 to 16 conducted in 2007, and participant observations and artifact reviews conducted during the summer of 2008 at Camp Strong. We constructed connections between outcomes related to camp participation and the processes that influenced those outcomes. We identified three outcome themes: (a) forming caring connections (including subthemes of awareness of commonalities and lack of isolation); (b) feeling reprieve and experiencing recreation (including subthemes of fun, anticipation of and reflection on camp, and a sense of freedom); and (c) increasing knowledge, attitudes, and skills (including subthemes of anger and conflict management, disclosure, skill learning and education, and medication adherence). All study participants mentioned these three themes to varying degrees. Several program processes influenced each outcome’s subthemes. Processes consisted of formal and informal policies and procedures, and social interactions. Table 3 summarizes outcome and process themes.

The three outcome themes were not discrete categories and appeared to be nested within each other in a temporal order. When campers formed caring connections, a space opened for feelings of reprieve (from worry and stigma at home) and recreation (to engage in fun activities) at camp and, in turn, this relaxed space provided an opportunity for the development of knowledge, attitudes, and skills. Next, we discuss the three main outcome themes, their subthemes, and the processes that influenced the outcomes.

Outcome 1: Forming Caring Connections

The theme of forming caring connections consisted of two subthemes: awareness of commonalities and lack of isolation. When campers felt connected to a positive, accepting community that cared for them, a space was created in which campers became more open to trying out new ideas, activities, and attitudes. Awareness of commonalities and lack of isolation fostered feelings of camp as a home. As one 16-year-old camper explained,

At home I’m like Clark Kent . . . but like here, I’m Superman. I’m just like, I’m more open, more talkative, more inspired. . . . ‘Cause when I’m at my home it’s like I’m hiding from everybody else. And that’s sad because I don’t want to, but it’s like I’m in the phone booth and it seem like I can’t even be around you, so, I just don’t communicate. Camp is more open, it’s just friends all over.

Next, we discuss each subtheme and their related processes. The first subtheme of forming caring connections was developing awareness of commonalities. One of the reasons given for the ease to form connections and feel accepted was that at camp, everyone dealt with the same issues related to HIV:

We all have that thing in common. It makes us all more at ease because we don’t have to, we’re not judging each other. Even though that everybody always judges outside of us [the campers]. Everybody judges. But [there], it’s like, we’re all the same. (Former camper [FC], age 17 [17])

A 15-year-old camper discussed how camp made her feel: “You’re just always getting reassured that it’s okay that you have this [HIV], and it’s just a good feeling.” Campers felt comfortable telling their stories to a supportive and caring audience and getting answers to their questions, which in turn served as stress relief.

Besides having HIV, the other major commonality between campers was that they needed to adhere to a strict medication regimen. The camp director mentioned that campers felt connected with similar others because they saw “143 other campers taking medications right alongside of them.” Campers discussed how they often learned from others taking the same kinds of medications effective ways to take their medications and how to deal with side effects. At home, campers might have been the only ones in their households taking medications. At camp, they saw most other campers taking them as well, which highlighted that they were not alone. Additionally, campers were able to share information about how to cope with side effects of different medications.

Another common experience among campers was grieving for friends and relatives who had passed away, often related to AIDS. At camp, youth dealt with feelings that arose from grieving in a supportive and nurturing manner, especially because so many campers faced similar losses. At home, campers’ expressions of grieving were typically stymied by the stigma associated with HIV/AIDS. At camp, youth discussed the deaths of family members and camp friends. Several campers overtly expressed their feelings about commemorating the anniversary of a loved one’s passing while at camp, and others treated them with respect and care for their grieving. Grieving was not ignored.

A major camp process that facilitated campers building awareness of commonalities was Teen Talk, a 1- to 2-hour education-based workshop held during four of the five nights of camp. Teen Talk was another adult-facilitated forum in which campers aged 12 to 16 connected because they were able to discuss matters related to HIV/AIDS only in this setting. Although the content of Teen Talk was confined to that context, the social and behavioral expectations carried over into other camp contexts...
such as in the cabins and dining hall. Because of Teen Talk, campers had a sense that they were not alone and that there were others like them: “I can relate to them and we relate to each other” (Camper [C], 16). Additionally, many campers did not have access to such a safe place to talk about HIV outside of camp; campers perceived discussing HIV at camp as a particularly valuable opportunity in their lives.

Conducting Teen Talk at night provided participants with a sense of mystery, quiet, and intimacy after a long active day. Younger campers were in bed by Teen Talk time, and older campers were less concerned about having the younger ones overhear them discuss HIV/AIDS and about needing to ensure the care of the younger ones. Several locations around camp provided the backdrop for Teen Talk, and all had different pros and cons. According to a Teen Talk facilitator, the most effective locations for group dynamics and learning were those where individuals in the group could hang back and observe if they wished. It was important for campers to be able to hide their emotions within the larger group if they needed to, because “[i]t be real deep at Teen Talk” (C, 14). Holding Teen Talk in these locations was also more effective if the lighting was low or dim. Good locations for Teen Talk included those that felt “contained” so that campers were not tempted to leave the group; the use of pillows on the floor helped encourage the campers to stay focused on the present activity, and not be distracted by other interesting things nearby. The nightly format of Teen Talk was predictable; ground rules were discussed, information was shared, and campers received candy afterwards. Finally, the facilitators modeled behavior expectations throughout their presentations of the material. Facilitators were seen as people who were approachable because of their extensive experience providing “raw” HIV/AIDS education to youth. If individuals felt uncomfortable asking a question in the large group setting of Teen Talk, they would take the facilitators aside during the day to ask their questions.

The second subtheme of forming caring connections was lack of isolation. In their often-isolated home environments, many campers lacked opportunities to interact with other youth and adults who were HIV positive. Campers reported many instances of feeling alone and isolated at home because of the stress of hiding their HIV status for fear of the negative impacts of disclosure. All but two campers indicated varying degrees of needing to live “a double life” because close friends at home were not aware of their status. The campers who did not report this were very open about their HIV status. Even when others did know a camper’s status, there remained a lack of a support system for sharing information and concerns

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about living with HIV/AIDS. Campers who had disclosed their status to others often found that their friends were just too uncomfortable to discuss it with them because of pity, fear, or disdain.

In contrast to the isolation felt at home, while at camp, youth felt that they were with others who were the same as them. There was no need to hide because everyone knew each other’s most closely held secret, and campers could easily share information and support about living with HIV/AIDS. At camp, there was no need to “shape shift,” or to align one’s presentation of self to match the context. Instead, campers more holistically integrated their identities at camp.

Campers created connections with others by taking interest in their lives, sharing their struggles, and providing encouragement to others to succeed. Camp exposed them to different ways of thinking, different attitudes, and different experiences through their interactions with others. Hearing how others solved problems provided inspiration for campers’ own lives. A 14-year-old camper explained:

Like we get to experience things that we won’t experience at home. Like you can’t just expect your parents to sit down and talk to you about things you’re gonna have to do in life. . . . They take us to Teen Talk, they take us to a quiet place. They don’t force you, they let you get your feelings out. When one person does, you all just let it out.

Emotions tended to run high during Teen Talk. This was one of the few (if not the only) places that campers had a caring group with whom to discuss their feelings. In Teen Talk, they interacted with nonjudgmental campers and staff who cared about their health and well-being, and who wanted to help them overcome difficulties and achieve their goals. However, some campers retained feelings of isolation within camp. For example, one youth discussed how he still felt different from other campers, even though he knew how similar they were. Most boys made fun of or ignored two male campers because of the boys’ developmental delays. For the two boys, their sense of belonging arose from connections they had with counselors, not other campers. Additionally, experiences of “drama” (i.e., miscommunication, gossip, jealousy) with other campers were present in about 15% of the camper interviews and focus groups.

Other camp processes influenced the outcome of forming caring connections. These processes included staff–camper interactions, long-term relationships, and outside-of-camp support. In staff–camper interactions, campers perceived counselors as having “an open heart,” wanting to hear what campers had to say, being concerned about their well-being, and being excited each summer to see campers return. Some campers mentioned how impressed they were that the counselors were all volunteers who gave up their time to work with them: “They do that for us? I appreciate it, I really do” (C, 15).

Staff demonstrated specific caring behaviors to connect with campers, such as genuine attention paid to campers, hugs, congratulatory hand claps, and active listening. Counselors physically interacted with campers, such as picking them up or teasing them. Additionally, all campers wore nametags with their first names on them, which facilitated calling all campers by name. These interactions were especially important for this population, because many people in campers’ lives avoid contact with them because of the stigma associated with HIV/AIDS. However, sometimes counselors were considered caring for other reasons. One focus group participant explained, “When we all leave the cabin, they put bags of toys and stuff on our bed.” In addition, counselors seemed adept at cheering up some campers by being funny or distracting them with fun activities. It appeared that some counselors were unprepared to deal with specific issues such as behavioral problems, incidents of sadness or grieving, and disagreements.

The culture of Camp Strong highly valued long-term relationships and involvement in camp. Desire to remain connected to camp over time signified a positive attitude and good decision making regarding one’s health. Continued attendance at camp signified continued life. For example, during staff training, the group enthusiastically clapped for and cheered a new counselor in training who had attended camp for more than 10 years.

The youth experienced caring people outside of camp, as well. Members of the medical and psychosocial teams were highly involved in campers’ lives, and this thread of connection made it both possible for youth to be successful at camp and at home. The relationship worked both ways. A social worker explained:

It gives me the opportunity to see them outside of their clinic visit. It gives me the opportunity to learn about them on a more intimate level and have them see me as more than just the social worker in the clinic. They see me and they want to talk to me, and it’s more of a relaxed atmosphere.

Campers also maintained connections with other campers outside of camp through text messaging, email, and other electronic means.

Youth development research has demonstrated the importance of relationships in youth contexts (e.g., Anderson-Butcher et al., 2004; Grossman & Rhodes, 2002; Paisley & Ferrari, 2005; Scales, Benson, & Mannes, 2006). Relationships drive programs. In this study, caring connections with individuals and the camp community...
supported campers’ feelings of reprieve and recreation, and increased knowledge, skills, and attitudes. Those campers with fewer or more frail social connections also experienced diminished outcomes in feelings of reprieve and recreation and in skill, knowledge, and attitude development. Conversely, strong positive experiences in one outcome area likely positively influenced those in other outcome areas. Across interview participants, those who reported high, medium, or low outcomes in any one area reported similar intensity in the other outcome categories. Because of camp connections, campers felt free of the need to “hide in the phone booth” and got to be “Superman,” their super selves. In this relaxed state, youth more thoroughly enjoyed the recreational activities camp had to offer.

**Outcome 2: Reprieve and Recreation**

The theme of feeling reprieve and experiencing recreation related to campers feeling that they had a reprieve from the stresses of everyday life, as well as opportunities for engaging in recreational activities. Campers experienced freedom from responsibilities and the need to hide at home, and freedom to engage in fun and challenging recreation activities. This theme consisted of three subthemes: camp activities are fun, camp is something that campers anticipate and reflect on all year, and there is a sense of freedom at camp. Processes that contributed to campers’ experiences of reprieve and recreation were camp activities (including Teen Talk), planning for the needs of campers, accessibility, and freedom from worry.

Youth spoke at length about their enjoyment of the fun activities at camp. Activities were fun because they were exciting, relaxing, novel, or interesting. They were also fun because they were available and accessible to campers. Additionally, the activities were platforms for social interactions. Campers saw camp as a place to enjoy themselves, to participate in activities that they normally would be unable to do at home because of lack of availability or accessibility (especially for those with mobility impairments). As a 10-year-old focus group participant explained, “I get to do all these fun activities, like archery, horseback riding, the zip line [an activity in which the participant rides or “zips” down a long, taut cable suspended between two tall poles], the rock climbing thing. Um, it’s something I don’t always get to do.” Campers also had fun engaging in social relationships both within the context of activities such as swimming and informally within unstructured time in the cabins or during meals. Campers learned how to do new things, such as shoot paintballs and arrows. Campers and counselors discussed how camp was “a vacation” for campers, which was especially important given the stressful context of their illnesses.

Most campers discussed in detail how they reflected on and looked forward to opportunities for reprieve and recreation all year. One camper told another camper, “This is the most fun I have all year.” The activities of anticipation and reflection were supported through camp mementos such as a memory book, diplomas, certificates, awards, and gifts from counselors.

At camp, campers were free from the responsibility to disclose their status to others, as well as the need to keep a secret from others. Additionally, they were free from responsibilities associated with school, work, and caring for siblings. As a counselor explained, camp is a place where they can feel safe and know that “these people are here take care of me, I can have all this fun, I can basically get away with things, [be] a real cut up.” It’s all in the spirit of good fun.

Campers reported feeling relief from the stress of both having to hide their HIV status at home, as well as their chaotic and often dangerous home environments. Although this category was similar to not feeling isolated, as discussed in the previous section, campers also discussed that this feeling of similarity and lack of isolation was something that was relaxing for them, a reprieve from the stresses associated with the stigma of HIV/AIDS. Without worry, campers were able to be free and fully engaged in the camp’s recreational activities.

Program processes that contributed most to the campers’ experiences of reprieve and recreation were camp activities, planning for the needs of campers, accessibility, and freedom from worry. Camp policies and procedures were fine-tuned over the years, resulting in ever-increasing efficiency and understanding of camper needs and behaviors. The caring relationships and sense of belonging that youth felt in camp helped them experience a sense of reprieve and recreation. This feeling in turn served as the foundation for the development of knowledge, skills, and attitudes. The reprieve-and-recreation outcome resulted from the processes of planning and implementing goals associated with providing a recreational experience for campers, and the activities found within camp, including Teen Talk.

Campers anticipated and looked forward to camp activities such as the dance, swimming, and the ropes course. The activities formed repeatable traditions that created a sense of security through achievement of expectations, “like a family reunion.” Camp activities were especially enjoyable if they were unique and had an element of danger and excitement, particularly the zip line, paintball, archery, and horseback riding.
Prior to camp, adult staff adjusted programming plans to accommodate the needs of campers. Staff planned activities to be age appropriate (i.e., older campers engaged in more complex activities), to account for fatigue issues associated with HIV/AIDS and the heat of late July in the southern United States, and to maintain high counselor–camper ratios (1:2). Additionally, the medical and psychosocial teams who addressed specific individuals’ needs and were a constant presence throughout camp supported campers.

Another way that feelings of reprieve and recreation were planned for at camp was through the structural and social accessibility of all activities, based on the facilities and programming philosophy. Discover Camp was intentional about making camp “barrier free,” and both campers and staff perceived that the camp activities were accommodating to all participants. For example, the ramp to the canoes was designed so that campers could typically enter canoes without assistance, and canoes could accommodate two or three helpers if necessary. Bean-bag chairs were placed into canoes so that campers with mobility or strength impairments could go out onto the lake in canoes. Additionally, the medical facilities made the camp experience available to youth; the health director described them:

From a medical standpoint, the cabins are air conditioned and well attended to, and so that kids who are medically frail can still have the opportunity to come. The medical center is well stocked, and so we can do injections. We have built good connections with the local emergency rooms.

Campers were free of other worries while at camp, which was another major reason that camp was a reprieve and opportunity for recreation. In camp, leadership positions were not available to campers (although a few counselor-in-training positions existed for former campers), and campers were not responsible for any camp operations or tasks (with the exception of one cabin-based volunteer task over the course of the week). The camp activities themselves were a less important reason that camp was enjoyed than was the sense of belonging to a group of supportive and caring people. Campers experienced this support within unstructured time (i.e., meals and rest times), and particularly felt it within Teen Talk. Here, campers were relieved of the burden of keeping their secret, and this made the Teen Talk program one of the most impactful experiences of camp. The feeling of reprieve from worries about home situations and keeping secrets allowed for a more open space in which to enjoy recreational activities with people who understood and cared for them, and this created an open space for increasing knowledge, attitudes, and skills.

Outcome 3: Increasing Knowledge, Skills, and Attitudes

Participants reported that while at camp, youth increased their positive attitudes, skills, and knowledge in several categories. These categories included anger and conflict management, disclosure, skill learning and education, and medication adherence. Campers achieved these specific outcomes within the context of the more general outcomes associated with camp participation, as discussed above. Increases in specific developmental outcomes became a separate theme because campers and staff viewed them as personal changes to campers’ self-concept and self-efficacy, as influenced by their camp participation. Processes contributing to campers’ development of knowledge, attitudes, and skills were education through Teen Talk and non-Teen Talk education.

A specific life skill many campers mentioned as an outcome of their participation at camp was the ability to manage their anger and to resolve conflicts with others. This outcome was particularly salient because social workers shared that many campers had anger management issues at home, either because of trauma, mental illness, or lack of role models to demonstrate effective ways to resolve problems. Camp exposed youth to people and situations that helped them deal with anger and conflict in productive ways. The atmosphere at camp was more peaceful than that usually found in campers’ home environments, where it was a valuable survival skill to be seen as tough and combative. Camp staff expected and planned for anger management problems to arise at camp because of these issues. Campers and counselors mentioned improvements over time in levels of self-control, gained by thinking through problems with counselors’ help. Camp provided resources for alternative attitudes toward dealing with problems. A 14-year-old camper discussed how camp helped him: “When I used to get angry, I just handle matters myself. I’d get in trouble. Here I don’t get in trouble. They just talk to me for a while, about like, how it’s not worth it.”

Campers frequently mentioned issues around disclosure of HIV status to other people, though counselors seemed less aware that this was a major issue in campers’ lives. Confidence to disclose seemed to be a function of age: the older campers were, the more likely they were to disclose. Their willingness to disclose also seemed based on the amount of time spent at camp. In addition, the more they participated in camp, the less likely they were to see HIV as stigmatizing, or something of which to be ashamed. Campers were often inspired to disclose their status through exposure to older or experienced campers, who freely shared information and stories about disclosure. Still, other campers refused to tell people their status for fear of damaging reactions.
Although campers wrestled with issues about disclosure, they gained technical skills regarding HIV/AIDS. This education included information about the HIV virus, taking and remembering to take medications, problem solving, and dating and relationships. Additionally, the informal context of camp allowed for a different method of transmission of information from that which was typically utilized in a medical or therapeutic setting. Campers were able to ask questions of people who had been through what they were going through, and did so in a nonjudgmental atmosphere where they “taught me how to continue on with what I want to do” (C, 16).

Besides disclosure, another HIV-specific outcome was that participants reported increasing their adherence to medication regimens. Campers’ responses to questions about medication adherence were consistent, indicating a shared belief system and common experiences. At camp, everyone took medications, so it was easier to remember to take them on time. At home, campers usually needed to be secretive or were busy with responsibilities, so it was easier to forget. Campers learned and shared techniques for swallowing pills that were often quite large, bad tasting, and nauseating, and for remembering to take them. This outcome also became integrated into regular health care procedures at home through doctors reinforcing the importance of techniques for medication adherence in the clinics. Campers gained information and coping techniques about HIV medications that related to the importance of taking them, side effects, reactions with other medications, and more. Additionally, interviews with former campers at Teen Forum indicated that medication adherence learned at camp changed campers’ clinical relationships with their doctors. At home, doctors were able to reference information learned at camp to reinforce adherence. An 18-year-old former camper shared her reasons for adhering to her medication regimen:

[Camp] helped me with my meds [medications]. Actually I’m on more medications, ‘cause I didn’t like medicine, I didn’t want to take none of it. But then I’d be seeing my friends not take their medicine, and I didn’t want my friends to die fast, so.

Teen Talk was the primary process mechanism for the development of knowledge, attitudes, and skills in campers through the exchange of information. Although it comprised only 4 to 8 hours out of approximately 120 possible hours spent at camp, Teen Talk seemed to have a disproportionately large impact on this outcome. Additionally, informal education took place during social interactions. These interactions typically occurred during unstructured cabin time, meals, and health care times.

**Discussion**

Understanding the role that contexts such as camp play in the development of youth is crucial to supporting administrators and staff of youth programs in their efforts to optimize outcomes for young people. This study highlighted that camp can be a powerful and supportive experience for youth with HIV/AIDS, a population about whom little is known outside of clinical and social work settings. Next, we discuss how each of the three outcomes of camp participation relates to other research findings.

Several studies highlight the importance of forming caring connections as a developmental support in youth programs (e.g., Anderson-Butcher et al., 2004; Lerner et al., 2005; Newton et al., 2007; Rhodes, 2004). Camp is an ideal setting for the development of positive relationships because of increased opportunities for unstructured and informal interactions between people as they go about daily routines in a cooperative living environment. Increased unstructured and informal interactions allow for higher levels of attention and support at camp than in school settings or after-school programs because of higher staff–camper ratios, a greater amount of time available during a week at residential camp, and intimacy found within close living quarters such as cabins.

The importance of camp friendships for youth with chronic illness has been well documented (Bluebond-Langner et al., 1991). In Bluebond-Langner et al.’s study, camp relationships for youth with cancer were characterized by qualities of empathy, understanding, and acceptance, and were unlike their relationships with healthy peers. Friendship quality is also crucial to the psychological health of youth with chronic illness because it affects their physical well-being (Helgeson, Reynolds, Escobar, Siminerio, & Becker, 2007). The creation and nurturement of connections with caring others is an important developmental support. Given that youth with chronic illness are more likely than their peers to engage in risky behaviors (Miauton, Narring, & Michaud, 2003), a caring social network is crucial to supporting their psychological health and ultimate well-being.

A sanctuary to become aware of commonalities and decrease feelings of isolation is more crucial in the lives of youth experiencing the profound effects of stigma than it is for those who face lesser feelings of isolation. Campers described the fear of labeling, stereotyping, separation, status loss, and discrimination (Link & Phelan, 2001) as pervasive in their lives. As Link and Phelan discussed, stigma is likely a key determinant of many life chances in the areas of psychological well-being, health, and housing.
Topics of stigma and disclosure frequently appeared in campers’ descriptions of why forming caring connections at camp were so important to them. Given the biopsychosocial nature of HIV/AIDS (Brown, Lourie, & Pao, 2000), a variety of interacting needs and issues emerged for youth during camp. Developing connections within a supportive social network can guard against the increased chances of depression, anxiety, and other psychopathological disorders (Marhefka et al., 2009).

To varying degrees, themes similar to feeling reprieve and experiencing recreation at camp have been identified in nearly all studies conducted in camps for youth with disabilities, as well as studies with more general populations (Brannan, Arick, & Fullerton, 1996; Fullerton, Brannan, & Arick, 2002; Goodwin & Staples, 2005; McAuliffe-Fogarty et al., 2007; Michalski, Mishna, Worthington, & Cummings, 2003). Camp Strong was a source of reprieve and recreation because it provided opportunities to experience flow (i.e., a completely focused motivational state in which the challenge of the activity balances the skills needed; Csikszentmihalyi, 1990) and positive affect, especially given the absence of stigma. Although the activities were not overly challenging to youth, they were able to engage fully in them, become distracted from other concerns in their lives, and feel free of stress. Participating in new recreational activities at camp provided avenues for maintaining physical health, interacting socially, and reducing stress. The activities and social experiences available at camp allowed for relative freedom not commonly found in other contexts.

Other studies examining the role of leisure in the lives of people living with HIV/AIDS have found that leisure and recreation activities are important for coping with the negative effects of the diagnosis and increasing health and quality of life (Caroleo, 2001; Florindo, 2007; Sausser, Dattilo, & Kivel, 2000). For example, Florindo found that leisure-time physical activity helped prevent fat accumulation in people with HIV/AIDS on HAART. Sausser and colleagues explored leisure in the lives of people with HIV/AIDS and found that there were physical, mental, and structural factors that influenced leisure participation, and that leisure was used as a way to negotiate perceptions of themselves. In Caroleo’s ethnographic study, through participation in a therapeutic recreation program, participants reported an increased ability to cope with anxiety attacks, and that they found a sense of community within the program. Although these studies were conducted with adults rather than youth, implications could be drawn that apply to youth. The findings from the above studies suggest that people living with HIV/AIDS have unique experiences within leisure and recreation contexts, and that program providers should be responsive to the needs of participants as well as intentional about using their programs to foster supportive participant outcomes, particularly coping outcomes.

Information and inspiration that increased knowledge, skills, and positive attitudes were communicated through the telling of personal stories, which has particular significance in cultures with a strong oral tradition (Struthers & Peden-McAlpine, 2005). Throughout Camp Strong, self-presentation and social support contributed to the campers’ constructed discourse of retaining hope through the struggle of living with HIV/AIDS (Miczo, 2003). Such opportunities to construct illness narratives have been effective in health promotion (Kennedy, Rogers, & Crossley, 2007; Mosack, Abbott, Singer, Weeks, & Rohena, 2005). As Collins (2000, p. 258) explained, “Experience as a criterion of meaning with practical images as its symbolic vehicles is a fundamental epistemological tenet in African American thought systems.” Although the purpose of this study was not to examine ethnicity-based communication styles, it appeared that there was a strong value and emphasis on the sharing of lived experiences as the impetus for personal growth and developmental advancement, and this was likely related to the fact that most campers were African American.

Within the informal context of camp are opportunities for different approaches to teaching and learning health care practices than are typically found in more formal medical settings. Some studies have addressed the specific issue of medication adherence at camp, highlighting its importance for the well-being of youth with chronic illness, and how camp practices can reinforce messages that come from health care providers. For example, a sense of normality, motivation, energy, willpower, support from parents, and positive attitude toward illness were associated with medication adherence at a camp for youth with diabetes (Kyngas, 2000). In another study, attitudes toward illness improved after participation in specialty camp programs (Austin & Huberty, 1993). Such outcomes are possible through the supportive relationships and opportunities for learning self-care found in the camp environment.

Conclusions

The findings from this study highlight that camp can be a powerful and supportive experience for youth with HIV/AIDS, a population about whom little is known outside of clinical and social work settings. The following recommendations for practitioners are organized around the three main outcomes found in this study.

Opportunities for campers to form caring connections can be planned for in every domain of camp, especially through staff selection and training procedures,
establishment of ground rules in educational sessions like Teen Talk, within cabins and during activities, and outside of camp. Staff should view campers as assets and resources to be developed, and not as problems to be fixed (Scales et al., 2006), and aim to intentionally influence youth’s long-term developmental outcomes through the camp experience (Walker, Marczak, Blyth, & Borden, 2005).

Given that this study showed that camp was a major influence on youth, additional opportunities should be provided for youth to connect with others through the medium of camp. Although campers formed friendship networks outside of camp, it was possible that some of the campers on the fringes of social groups might have lacked access to these networks. To ensure equitable access to social networks after camp, camp administrators could provide formal and informal opportunities for further relationship building and nurturing for campers. Doing so would provide further contact between the positive social context of camp and individuals, as well as provide opportunities to teach others about HIV/AIDS through advocacy and educational efforts. This would also influence the development of a sense of belonging to a larger, supportive community.

Further opportunities for forming caring connections could include increased time to share concerns and information, ways for campers to discover similarities with other campers, and engaging in fun recreation activities that make these other goals palpable to youth. Supportive adults can foster interactions between campers and between campers and staff, as well. Youth living with HIV/AIDS typically lack an array of effective supports for their efforts to disclose their status to others and to adhere to medication regimens. Camp can be an important intervention tool to support youth in their efforts to grapple with adversity while building resiliency (Nicholas, Picone, & Selkirk, 2011).

Opportunities to feel reprieve and experience recreation are already in place at Camp Strong. What should also be considered is how to balance recreational and educational goals for campers, and how to intertwine learning opportunities into the fun and relaxing activities of camp. Camp could provide more opportunities to build physical recreational skills because these skills could carry over into campers’ lives at home, and help to ameliorate their “couch potato tendencies.” Campers could also select certain activities in which to participate as individuals rather than groups, so that they could feel a sense of choice and control in their camp experiences.

Several researchers have suggested that people with HIV/AIDS face unique barriers in their leisure and recreation (Grossman et al., 1994; Grossman, 1997; Pearce, 1994; Sausser et al., 2000). Yet, engagement in leisure and recreation can provide a sense of self-determination, coping, social involvement, identity development, and personal fulfillment that increases the quality of life. Specific recommendations for negotiating barriers to recreation participation include

- Adapting activities to account for fatigue issues;
- Increasing opportunities for structured and unstructured physical activity;
- Avoiding offering activities that are simply diverisonal or entertaining (Caroleo, 1994) by being intentional about desired developmental outcomes of participation;
- Supporting youth in determining and achieving leisure and recreation goals;
- Integrating leisure and recreation into all contexts in which youth are involved, such as clinics, hospice and other care facilities, home, and school; and
- Highlighting people with HIV/AIDS engaging in various recreation and leisure activities as role models to encourage participation by others.

Camp programmers and facilitators should intentionally integrate opportunities to increase skills, knowledge, and positive attitudes. For example, after each activity, a 5-minute debriefing session could be held so that campers could reflect on their experiences. Nightly cabin-based debriefing sessions could also be conducted, perhaps by the psychosocial team or trained facilitators. These opportunities should be age specific; that is, older campers tend to be more open to self-reflection and sharing than younger campers, and would likely be more amenable to increased opportunities for self-development.

Additionally, this article adds to the literature on youth with chronic illness. Often, health care providers narrowly focus on the medical aspects of illness and neglect other parts of youth’s lives. This study highlighted several issues that youth face as they cope with growing up with a chronic illness. Findings support the idea that a variety of methods and holistic approaches are necessary to effectively educate and support youth in their development. This study also linked the disability and youth-development literature. To employ a public health or social work perspective would have uncovered only part of the outcomes associated with camp participation, particularly medication adherence and adult life skills.

Finally, the study findings reinforce that camp can be an important support in the lives of youth. In an era of decreased funding for social programs such as after-school programs and camps, this study showed that camp can support the development of youth, especially those with chronic illness such as HIV/AIDS.
Authors’ Note

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References


Kang, E., Mellins, C. A., Yiu Kee Ng, W., Robinson, L.-G., & Abrams, E. J. (2008). Standing between two worlds in Harlem: A developmental psychopathology perspective of perinatally acquired human immunodeficiency virus and...


AIDS: Insights from youths living with the virus (pp. 105-126). Westport, CT: Praeger.


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