“When I went to camp, it made me free”: A longitudinal qualitative study of a residential intervention for adolescents living with HIV in the UK

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A R T I C L E   I N F O

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A B S T R A C T

There are nearly two million children living with HIV globally. This population faces many challenges impacting on their wellbeing. One approach to mitigating the effect of HIV on children living with the condition is to offer psychosocial interventions residentially. There has been limited published research on the effects of residential interventions (camps) and, in particular, whether these are maintained over time. This study explored the experiences and perceived impact of attending a camp for young people living with HIV in the UK. Semi-structured in-depth interviews were conducted with eleven young people (aged 12–16 years, six female) six weeks after camp. Eight of these participants completed a follow-up interview six months after camp. The data were analysed using thematic analysis.

Six main themes were identified: connecting with new friends and feeling less alone; gaining HIV knowledge and learning about living with HIV; developing a positive self-image; communicating more purposefully; becoming more autonomous; and a desire to engage further with the HIV community. The majority of these themes were reported both at the six week and six month follow-up points. Participants felt that the intervention had increased their confidence, decreased their anxiety about sharing their HIV status and widened their support network. Practice and research implications are outlined.

1. Introduction

Globally there were an estimated 1.8 million children living with HIV in 2015, mostly in Sub-Saharan Africa (UNAIDS, 2016). With advances in antiretroviral therapy (ART), children born with HIV can have comparable life expectancy to their HIV-negative counterparts (Wada et al., 2014). There are, however, a number of challenges for children living with the condition. These include adjusting to being told that one is HIV-positive (paediatric disclosure or HIV naming), managing ART adherence in the context of long histories of medication use with suboptimal regimens (Sohn & Hazra, 2013), and anxiety about sharing one’s HIV status with others (onward disclosure). In addition, some young people living with HIV have experienced multiple car-taking transitions with parental illness or death and other stressors associated with living with a chronic illness (e.g., hospitalisations, missed school and social opportunities, and pain) (Mellins & Malee, 2013). Some challenges, for example managing feelings of isolation, may be particularly relevant in low HIV prevalence contexts (Hogwood, Campbell, & Butler, 2013), for example in the UK, where the estimated prevalence across all ages is 1.6 per 1000 of the population (PHE, 2016).

There is evidence of higher levels of emotional and behavioural problems, including psychiatric disorders, in young people living with perinatally acquired HIV (infected from birth) compared to young people unaffected by HIV (Mellins & Malee, 2013). There remain relatively few psychosocial interventions, however, for children affected by HIV (King, De Silva, Stein, & Patel, 2009). Offering psychosocial interventions residentially (camps) is one approach offered to children with chronic conditions as a way to reduce isolation, increase self-esteem and wellbeing, enhance treatment adherence and increase condition-specific knowledge. Camps refer to programmes of educational, creative, recreational and social activities that take place in a setting where participants remain overnight. Health-related information and support is provided outside of the clinic environment, with peer support often a key component. There is evidence in other chronic conditions (e.g., obesity, cancer, diabetes and asthma) of increased youth self-esteem after attending camps (Odar, Canter, & Roberts, 2013) although no quantitative assessment of outcomes for young people with HIV. There have also been qualitative studies with children living with HIV in the US exploring the experience of camps (Gillard, Witt, & Watts, 2011)

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suggesting that they can help in the formation of caring connections, providing reprieve and recreation, and increased knowledge, skills and attitudes, through facilitating a sense of belonging, enjoyment, freedom to be oneself and personal growth. There have been no longitudinal investigations of whether the benefits of camp are perceived to be maintained over time. This is important given the significant resources required to offer these interventions.

This UK study presents a qualitative investigation of young peoples’ experience of a residential support camp conducted both at the end of the intervention and six months after, using representative sampling methods. It aimed to answer what the experiences and perceived consequences of attending camp were over time.

2. Methods

2.1. Study design

The study used a longitudinal qualitative design. Data were derived from 19 semi-structured interviews with 11 young people aged 12 to 16 years at two time points after a residential intervention held in August 2015. The first time point (six weeks after camp) was chosen as it allowed for time for the interviews to be arranged. In addition, participants had returned to school or college after the summer and, therefore, would be able to reflect on the perceived impact of camp on their everyday lives. The six month time point was selected to coincide with the administration of self-report measures that evaluated the impact of camp.

2.2. Intervention

The intervention was provided by the UK Children’s HIV Association (CHIVA) and was a week-long intensive peer engagement support camp with individual emotional support. Professional staff consisted of a Social Worker, Child Participation experts, and a Nurse. A volunteer team comprised Camp Leaders; peer mentors aged 18–24 who live with HIV and Key Workers of varied professional backgrounds and including people living with HIV and adults who previously attended camp when younger as participants. Creative and performing arts workshops (music, poetry, drama and art) encouraged expression of experiences of growing up with HIV. Sporting activities included rafting, football and volleyball. There were three participatory HIV-related workshops. An HIV information workshop (delivered separately for older and young camp attendees) included information on HIV transmission and rights. An HIV experience workshop examined issues of importance for attendees and reflection on how HIV was related to these. Scenarios where young people told others about their HIV were role played and advice was given on how to share one’s status. A sexual health workshop enabled attendees to have sexual health questions answered. This workshop was delivered separately to males and females, and each gender attended the workshop separately in younger and older groups. The aims of the camp were to address isolation and facilitate peer friendships, increase knowledge and understanding of living with HIV, and improve confidence and self-esteem.

The intervention was offered to all 12–16 year olds living with HIV in the UK. The inclusion of young adolescents at camp is in line with recommendations to complete the naming process earlier (WHO, 2011) and with calls to provide interventions to aid decision-making about onward HIV disclosure in this population (Evangelì & Foster, 2014). All of the young people who wished to attend were offered a place (n = 77). Forty eight (62%) of the camp attendees had not attended previously and 45 (58%) were not receiving any specialized HIV support services.

2.3. Sample

Young people were eligible to be interviewed if they had parental consent and had given their consent or assent to take part in a larger intervention evaluation. There were no additional exclusion criteria. At the post-camp time point, six females and five males aged 12 to 16 were interviewed. See Table 1 for participant characteristics.

2.4. Ethics

The study received ethical approval from Royal Holloway University of London Psychology Department Ethics Committee. Parental consent was obtained for all interviewees. Additionally consent was obtained from the 16 year olds and assent for those under 16 years.

2.5. Procedure

Separate interview guides were developed for the six week and six month time points. Both were piloted with members of the UK CHIVA Youth Committee (CYC) prior to being used for data collection. The CYC consists of adolescents and young adults living with HIV. Members were e-mailed by the CYC coordinator and provided feedback on the content and phrasing of the interview guides.

Interviews at six weeks focused on assessing experiences of camp (e.g., “What kinds of things did you do at camp?”, “What kinds of things did you learn at camp?”). Interviews at six months also asked about camp (e.g., “Looking back, how do you feel about camp now?”) but the emphasis was on experiences since camp (e.g., “How often have you talked to other people that you met at camp?”). Care was taken to avoid leading and closed questions throughout. The first author was present during camp but did not interact directly with participants until they were interviewed.

Twelve participants were selected by random sampling stratified by age and sex (two male and two females from each of three age bands). Two males refused (one said that he was too busy, one had concerns about his level of English) and were replaced with an additional two young people. Camp organisers subsequently suggested removing one potential participant due to concerns for their well-being. Interviews took place with the first author in private rooms at either a hospital clinic or at a known support organisation approximately six weeks after the end of camp. For the six-month follow-up interviews, all 11 of the attendees who were interviewed at the post-camp stage were invited to participate again. Two could not be contacted and one agreed to participate after the appropriate time period expired. Eight interviews were therefore completed. Interviews took place with the first author in a private room at a hospital, local community organisation or the young person’s home.

Camp attendees who completed interviews were compensated with a voucher worth £10 per interview. The length of interviews varied from 20 min to over 1 h. All interviews were recorded by an audio recorder and subsequently transcribed verbatim by the first author.

<table>
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<th>Name*</th>
<th>Sex</th>
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<th>Birth region</th>
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<th>First time at camp?</th>
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</tbody>
</table>

*Names have been changed for anonymity.
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