**“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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**Abstract**

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.

**Keywords: HIV; Camp; Residential; Psychosocial; Intervention; Adolescent**

1. **Introduction**

Globally there were an estimated 1.8 million children living with HIV in 2015, mostly in Sub-Saharan Africa ([UNAIDS, 2016](#_ENREF_21)). With advances in antiretroviral therapy (ART), children born with HIV can have comparable life expectancy to their HIV-negative counterparts ([Wada et al., 2014](#_ENREF_22)). 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](#_ENREF_20)), and anxiety about sharing one’s HIV status with others (onward disclosure). In addition, some young people living with HIV have experienced multiple caretaking 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](#_ENREF_13)). Some challenges, for example managing feelings of isolation, may be particularly relevant in low HIV prevalence contexts ([Hogwood, Campbell, & Butler, 2013](#_ENREF_10)), for example in the UK, where the estimated prevalence across all ages is 1.6 per 1000 of the population ([PHE, 2016](#_ENREF_18)).

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](#_ENREF_13)). There remain relatively few psychosocial interventions, however, for children affected by HIV ([King, De Silva, Stein, & Patel, 2009](#_ENREF_11)). 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](#_ENREF_17)) 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](#_ENREF_9)) 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.

1. **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](#_ENREF_23)) and with calls to provide interventions to aid decision-making about onward HIV disclosure in this population ([Evangeli & Foster, 2014](#_ENREF_5)). 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.

**Table 1 here**

**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 twenty minutes to over one hour. All interviews were recorded by an audio recorder and subsequently transcribed verbatim by the first author.

**2.6 Analysis**

Thematic analysis ([Braun & Clarke, 2006](#_ENREF_1)) was used to generate themes and sub-themes, finding common elements across the reported experiences of the interviewees. An inductive approach was used. The first author transcribed and read through all interviews. Each line was then coded. These codes were reviewed and sub-themes were generated. These were then concentrated further into main themes, which focused both on the time at camp and its subsequent impact. All coding and consolidating of themes was carried out by the first author and subsequently reviewed by the second author. Discrepancies between authors were resolved through discussion until agreement was reached.

**2.7 Quality**

Quality standards were used to inform this study ([Elliott, Fischer, & Rennie, 1999](#_ENREF_4)). The sample was situated (through providing demographic data), the analysis was grounded in examples, credibility checks of the first author’s coding were used (by the second author) and reflexivity was maintained (through repeated discussion between the first and second author).

1. **Results**

Six overarching themes were identified. All interviewees referred to these topics to varying degrees. The themes relate to the week spent at camp as well as the period following camp. The findings are presented according to theme rather than time point as the majority of themes were elicited from interviews at both time points.

* 1. **Connecting with new friends and feeling less alone**

Whether experiencing camp for the first time or as a returning attendee, meeting new people also living with HIV appeared to be the main reported advantage of camp. This theme was reported at the six week interviews, which focused directly on the camp experience. Communication throughout camp and late night socializing occurred often and young people used this time to form deep bonds with their peers.

*“My friends were all in the corridor and we would just stay up late and sit in the hallway talking and we could talk about anything. We could be talking about the past and all the stuff that we wouldn’t talk to our normal friends about.”* [Miriam – six weeks]

*“We’d stay up until midnight or one o’clock in the morning having midnight chats about life, relationships, HIV and all that stuff.”* [Sarah – six weeks]

The comparison of camp friends to home friends highlighted the depth of new relationships, particular commented upon by female participants (males did not reflect on connections with new friends and feeling less alone at the same rate or depth).

“*Because as much as I love my best friends, they can never relate to me. They can say they understand but deep down they truly don’t and like, knowing someone that does have HIV can like, complete everything”* [Kyra – six weeks]

*“[We] were closer and it felt natural to be able to talk about things like that ‘cause Iʼd like to bring it up with my other friends who arenʼt HIV positive but they would [...] be trying to react appropriately […] but actually sometimes you just want to talk. Youʼre not trying to get a reaction and thatʼs, thatʼs what was much easier at camp cause weʼd just talk, we wouldnʼt have to say.”* [Shazia – six weeks]

**3.2 Gaining HIV knowledge and learning about living with HIV**

This theme was elicited from interviews at both time points. The two main workshops at camp focused on HIV facts and sharing HIV experiences. Attendees reported learning new information about HIV and their rights, even if they had attended camp previously.

*“Talking to people and the workshops were really good because before I literally did not know anything. I just knew I had it and that was really it but now I know sort of the basics of how itʼs functioning in my body and how it works and just speaking to people in general, it helps a lot.”* [Kyra – six months]

*“I found out that I have a lot more rights than I thought I did.”* [Shazia – six weeks]

The workshops also promoted discussion among participants and encouraged young people to express their feelings on topics like onward HIV disclosure (sharing their HIV status with others) and living with HIV.

*“The workshop helped me out […] because people had like stories […] and it made me realize that everyone’s been through this. I thought I was the only one.”* [Junior – six months]

*“I learned from the workers that you don’t have to be scared that you have it. It’s something built within you and don’t shut it down and feel bad about it. […] It helped me a lot because before I used to be so scared and so upset and I didn’t feel as if I could tell anyone. Well, I told people but I didn’t really talk about it and it’s hard not to tell someone and really talk about it but now I feel I can be open.”* [Kyra – six weeks]

*“It was interesting to hear how some people have gone through loads of stigma around things and hear how they’ve overcome them so that it’s possible if I’m in a similar situation for me to [be prepared]”* [Luke – six weeks]

*“I never knew other people felt like that […] I learned that like some people have been really affected by it. I never saw it like that. […] vice versa from me, like they were so affected by it and they saw that it didn’t have an effect on me and they kind of saw that there’s nothing to worry about”* [Anthony – six weeks]

Creating an open environment where young people did not have to worry about what they say or how they speak empowered them to share personal stories and learn from others’ experiences.

*“I was angry and I didn’t tell anyone I was angry. When I went to camp, it made me free. It made me realize there’s actually more people that has it at my age.”* [Junior – six months]

*“We learned about…that we can talk to each other about it and some people like to tell people about it but it’s not everybody who likes to tell someone about it.”* [Emma – six weeks]

The knowledge gains and communication about HIV appeared to normalize the condition and provide young people with some control over their diagnosis. Interviewees even described situations in which they felt comfortable making jokes about HIV.

*“I feel like we’re the same as everyone else and just because we have HIV, it doesn’t mean we should be treated differently”* [Miriam – six weeks]

*“I’m as normal as anybody and that I can still have my goals and my future and have the family I want.”* [Emma – six weeks]

“Y*ou can make jokes out of it because you’ve got the same thing whereas if someone never had HIV and the person that didn’t have it made a joke about the person that did, it would be quite weird and strange.”* [Kyra – six weeks]

**3.3 Developing positive self-image and prospects for the future**

Gaining confidence as a result of experiences at camp was one of the most prevalent themes at the six week interviews. Increased confidence was reported to have facilitated communication and the forming of relationships.

*“I think being able to see that there are other people like me going through the same sorts of things has made me feel like I’m not alone and it’s a confidence booster.”* [Luke – six weeks]

*“Yeah I was scared to tell people that I’ve got ‘cause they might treat me different but [camp] made me feel not scared anymore.”* [Junior – six weeks]

Relationships with camp staff served as sources of support and inspiration as young people saw first-hand what they could achieve as someone living with HIV. Staff members dissipated fears about the future and provided hope.

*“It did change a lot for me because before I was like so scared, like “what if the whole school finds out? Oh my gosh I might lose a lot of friends.” Then after that I just had to think to myself if they really are a true friend, I would have told them already and number two, they wouldn’t push me away just for my illness. They would love me for who I am and my illness doesn’t define who I am.”* [Kyra – six weeks]

Information about preventing mother to child transmission of HIV made one interviewee optimistic about the ability to have her own children, which she did not have prior to camp.

*“That can impact your future but knowing that if you just keep yourself healthy, you wonʼt have to worry about your child being the way you are if you just keep yourself all well.”* [Kyra – six weeks]

**3.4 Communicating more purposefully**

All interviewees reported keeping in touch with friends from camp at both the six week and six month time points. Young people created an extensive online support network, through social media (WhatsApp, Facebook, Instagram and Snapchat), which was not previously available to them. They used this communication to encourage each other when struggling with medication or discussing romantic relationships.

*“[*We use it] *nearly all the time because we have a group chat and we just talk, see how everyone’s coping [...] Like if we’ve got questions, I wouldn’t ask my mum… I’d ask them cause they have it as well and I try to have their view.”* [Junior – six months]

*“Sometimes I […] help them with complicated relationships.”* [Emma – six weeks]

Young people reported asking more questions to caregivers, clinic staff and peers from camp after returning home, to further their HIV knowledge.

*“I think I’m fairly self-sufficient in understanding things now cause I have people I can contact […] When I want to know I would ask my friends and my boyfriend or doctors or [CHIVA] online and it works quite well. But I didn’t have the reassurance to actually go out and do that if I was, before camp.”* [Shazia – six months]

Furthermore, interviewees stated that they had educated people from home with the information they learned from camp. This occurred with both family members and HIV-negative individuals from their social network or school.

*“The people that I have told that I’m HIV positive, I tell them what happened at camp and inform them on the facts about it. I feel like if I learn something, I should give it back out to the whole world because so many people get the wrong idea of having HIV.”* [Kyra – six weeks]

*“It was easier [to talk to her after camp…] because I know more about HIV and what it does.”* [Oliver – six weeks]

**3.5 Becoming more autonomous**

Increased autonomy (reported at both time points) manifested itself in various forms such as independence in clinic, developing healthy romantic relationships or improved adherence to anti-retroviral treatment.

*“It was a lot like not letting it define who you are and just being you and like, in life so I was like “yeah I’m gonna do that” and ever since camp I’ve been taking my medication.”* [Chloe – six weeks]

*“I don’t see it as such a negative thing, like I don’t see it as a big thing anymore. Now I feel like I’m ok with what I have, you have to live with it in order to be healthy and […] I’m just taking [my medication] consistently now.”* [Kyra – six months]

Interviewees also realized the importance of communication and began feeling more comfortable with self-expression after their time at camp. This was reported in relation to situations with both HIV-positive and HIV-negative individuals.

*“I didn’t know that everyone was going to have it but everyone had it and everyone was talking about it and that made me confident if you get what I mean. Got me confident to talk about it as well so when I came home I was confident to talk about it as well.”* [Junior – six weeks]

Part of being more autonomous was feeling self-assured in how to deal with specific situations.

*“I have more of a confidence in my decisions after camp … I’ve just felt like whatever I decide, I can do it and I can choose that and that is was it is for me and I don’t need to go asking people and making sure everything’s good with them if it’s good with me.”* [Shazia – six months]

**3.6 Feeling motivated to continue engaging with the HIV community**

The young people all had positive expectations of camp but these largely focused on learning new facts or participating in enjoyable activities. What they did not expect was how meaningful the experience would become and the desire to return to camp, either as an attendee or to become staff members and have the opportunity to inspire new young people. This theme was apparent at both the six week and six month time points.

*“I want to make other people feel comfortable around camp and stuff plus other key workers made me feel comfortable”* [Junior – six weeks]

*“Be able to help more people get through troubles ‘cause I’ve been through experiences and there’ll be young people coming through and some people who are like me, coming from isolated areas of the country where there aren’t many HIV people associations which can help.”* [Luke – six weeks]

For many young people, particularly the older adolescents, there was a newfound interest in undertaking advocacy work after attending camp.

*“There are so many people that struggle […] All I have to do is take medication so to have people that are actually ill and to know about those people makes me want to really help them and for them to not have to worry about it anymore. Being at camp […] I was more aware of it and I’m more motivated to help.”* [Shazia – six weeks]

One example discussed by participants was of joining the CHIVA Youth Committee.

*“I started being involved in many things, loads and loads of meetings and doctors conferences which are all very interesting and fun and this year I’ve been doing symposiums.”* [Luke – six weeks]

*“I like it. I travel places that I wouldn’t have gone at this age. I live in the middle of nowhere basically and I think it’s just me and a few other people in this town that are HIV-positive. I get to bring back my experiences here and I think it can benefit me and hopefully other people.”* [Isaac – six months]

1. **Discussion**

This qualitative study aimed to explore the meaning and impact of a residential intervention for young people aged 12-16 living with HIV in the UK. Overall, interviewees reported very positive feelings about the camp experience with positive developments since returning home. There was evidence of positive peer relationships (particularly in females), increased knowledge of living with HIV, and improved self-confidence, consistent with camp aims. Experiencing the camp as normalizing was reflected in several of the themes and this may have been a powerful therapeutic process for young people, impacting on attitudes towards HIV. In addition, the supportive and engaging environment at camp, with opportunities to interact with staff and peers, may have facilitated the achievement of camp aims, in line with the positive youth development approach ([Lerner, Almerigi, Theokas, & Lerner, 2005](#_ENREF_12)).

The perceived benefits of the camp in forming relationships and gaining HIV knowledge and skills are similar to those reported in previous studies in the US ([Gillard & Allsop, 2016](#_ENREF_8); [Gillard et al., 2011](#_ENREF_9)). The findings suggesting more positive self-perception are consistent with quantitative studies with children living with other chronic conditions ([Odar et al., 2013](#_ENREF_17)) and with our quantitative evaluation of this camp ([Evangeli, Lut, & Ely, 2016](#_ENREF_6)).

One of the main benefits of camp appeared to be the support system young people gained. Over half the attendees at camp did not access specialist support services, partly due to geographical isolation and the scarcity of specialist support across the UK. As such the young people have very limited opportunities to share experiences and communicate with peers. In relation to those with access to HIV support, there is some evidence of positive benefits of support groups for children living with HIV ([Brothers, Harper, Fernandez, Hosek, & Adolescent Trials Network for, 2014](#_ENREF_2); [Funck-Brentano et al., 2005](#_ENREF_7); [Midtbo, Shirima, Skovdal, & Daniel, 2012](#_ENREF_14); [Mupambireyi, Bernays, Bwakura-Dangarembizi, & Cowan, 2014](#_ENREF_16)). It may be that these effects are enhanced in a context with a larger number of peers with diverse experiences to learn from.

One advantage of our longitudinal study was its ability to collect data on whether young people kept in touch with others from camp over time. Important peer relationships remained for some attendees, facilitated by social media. Young people reported learning new information about HIV (for example the impact of the virus on the body, and HIV rights) despite some having attended camp before, also consistent with quantitative findings ([Evangeli et al., 2016](#_ENREF_6)). Even if the same material is covered in camp workshops as in clinic, there may be a number of reasons why engagement with and retention of information is enhanced at camp. These include the additional time offered, the range of interactive methods used (e.g., group work, art, games, quizzes), and the less pressured learning environment. In addition, modeling from peers within psychosocial interventions may affect knowledge and subsequently clinically-relevant outcomes such as adherence to medication ([Reisner et al., 2009](#_ENREF_19)). The reports of post-camp motivation to engage with the HIV community and act as an advocate are encouraging in light of evidence showing the benefits of volunteering in other adolescent populations ([Miller et al., 2002](#_ENREF_15)).

* 1. **Strengths and limitations**

The most significant methodological strength of this evaluation is that interviews were repeated and took place over an extended period of time. This enabled us to show a lasting perceived impact of camp. The evaluation suggests that for the young people, there was a change in HIV knowledge and self-perception, which may be determinants of important behavioural and affective outcomes (e.g., adherence, well-being). There was a good response and retention rate for the study and sampling was representative. The sample size was small, however, and it may have been that data saturation was not reached for all themes. Regarding generalizability, there was evidence that participants were representative of camp attendees in terms of age, sex, region of birth, UK region and previous camp attendance. In addition, participants were representative of the UK population of adolescents living with HIV in relation to sex and region of birth ([CHIPS, 2015](#_ENREF_3)).

**4.2 Practice and research implications and conclusions**

The reports of the perceived ongoing benefits of a residential intervention extend previous findings and are part of a growing evidence base. This may serve to support the provision of residential interventions globally. Further research should examine the facilitators and barriers to remaining in contact with fellow camp attendees, as well as the specific aspects of HIV knowledge gained by participants. Studies on the experience of other stakeholders (e.g., clinic staff and caregivers) could be undertaken. In addition, quantitative studies should assess the impact of camps using robust designs, including examination of whether age and sex moderate effects. Finally, efforts should be made to examine and enhance the effects of the post intervention phase (e.g., considering sustainable and effective peer support or booster sessions).

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**Highlights**

* There are nearly two million children living with HIV
* Residential psychosocial interventions (camps) may help this population
* Interviews were carried out with young people after attending a UK camp
* Spending time with other young people living with HIV was very important
* Increased confidence, less HIV disclosure anxiety and greater support was reported

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Name \*** | **Sex** | **Age at camp** | **Age at HIV naming** | **Birth region** | **UK hospital region** | **First time at camp?** |
| Emma | F | 12 | 10 | UK | London | Yes |
| Miriam | F | 12 | 10 | Other Europe | London | Yes |
| Oliver | M | 12 | 4 | Africa | North | No |
| Kyra | F | 13 | 12 | UK | London | Yes |
| Chloe | F | 14 | 10 | Africa | Midlands | Yes |
| Junior | M | 15 | 13 | Africa | North | Yes |
| Isaac | M | 15 | 12 | Africa | North | No |
| Sarah | F | 15 | 11 | UK | North | No |
| Anthony | M | 16 | 10 | Africa | North | No |
| Luke | M | 16 | 12 | UK | South West | No |
| Shazia | F | 16 | 13 | UK | South West | Yes |

**Table 1. Interviewee characteristics** – \*Names have been changed for anonymity.