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Freedom to Be: The Impact of CHIVA camp

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Abstract

This paper presents the importance of peer support for young people growing up with HIV in the UK. We provide insight in to some of the challenges young people experience, by reviewing the impact of CHIVA camp (Freedom to Be (F2B)). The socio-demographics of camp participants over the last eight years are shown. Young people's voices are included to demonstrate impact.

Introduction

As of April 2016, a total of 905 children and young people were alive and in active follow-up at a paediatric clinic in the UK or Ireland [1]. Just over half (53%) were female, 50% were born in the UK or Ireland, 78% were of black African ethnicity, and nearly all (93%) were known to have been infected through mother-to-child transmission [1]. It is recognised that some young people living with HIV struggle with following their medication regimens as prescribed, finding out about their HIV status and managing personal relationships, including sexual behaviour and sharing their status with others [2].

Many children and young people living with HIV have experienced additional psychosocial challenges including bereavements, poverty and isolation [3]. Growing up with a highly stigmatised health diagnosis means that for many children and young people only their closest family members know their diagnosis and they are unable to talk about HIV with friends, siblings and other family members.

Globally, there are limited psychosocial interventions for children and young people living with HIV [4]. Furthermore, evaluations measuring the impact of these existing programmes are scarce. In the UK, a limited number of local community organisations exist to provide support to people living with HIV. Resources for providing these types of activities are vulnerable to budget cuts and attendance by the young people is not consistent.

Freedom To Be (F2B)

F2B is a residential camp offered by Children's HIV Association (CHIVA) since 2010 to young people who are living with and aware of their HIV status in the UK and Ireland. Camp aims to enhance HIV knowledge and understanding; address the high level of isolation experienced in relation to growing up with HIV; enhance confidence, self-esteem and hope; and build aspiration for the future

Throughout the weeklong camp, young people participate in knowledge workshops, sports and creative activities that take place on campgrounds or off site in the case of canoeing, for example. Often activities help build teamwork skills, confidence, and encourage campers to face fears or take part in new experiences. Creative activities such as music, art or poetry promote self-reflection and often elicit cathartic emotional responses. Many aspects of camp address isolation, by building resilience and support networks, and enhance knowledge and understanding through engaging youth-focused educational workshops.

The age range has changed over time with campers between 13-17 years being eligible until 2015 when it was reduced to 12-16 years and subsequently changed to include 11-16 year olds since. This has been influenced in part by recommendations to begin the process of naming HIV to children earlier, with CHIVA striving to minimise the time between naming and access to peer support and HIV education. Once young people have exceeded the eligible age for attendance as a camper, they have the opportunity to apply to return as 'Camp Leaders', young people living with HIV who can share experiences and support, then later 'Key Workers' to support young people at camp; both roles are voluntary. Entering into such roles as young adults further contributes to personal development as they learn to manage leadership roles and provide peer support to new camp attendees.

All staff and volunteers; camp leaders and key workers, are provided with training prior to camp to include child protection and safeguarding. The training course covers providing emotional support to children. Strategies around managing behaviour and de-escalation approaches. At camp volunteers have designated supervisors who provide daily supervision meetings to support the volunteers in their roles and address particular issues. The group supervision approach helps to ensure consistency across the team and to provide a daily debriefing and support opportunity for what is a demanding and challenging role at times. Camp attendees sign behaviour agreements prior to attending camp and a behaviour management system is in place at camp to ensure the safety of all young people and that behaviour issues are addressed promptly, effectively and consistently.

Camp socio-demographics are presented below. Broad geographical representation is achieved each year with participants attending from all regions of the UK and Ireland. CHIVA allocates places based on previous attendance and access to support outside of clinic all year round, ensuring that the most isolated children can benefit from camp.

[Table 1 – Socio-demographic information for camp attendees 2010-2017]

	2010	2011	2012	2013	2014	2015	2016	2017
Gender								
Male	27	37	44	47	50	34	37	52
Female	49	60	57	50	51	43	44	40
Attendance								
Returning	0	51	44	58	54	25	31	38
New	79	46	57	39	47	48	48	54
Access to support services								
Yes	39	45	27	43	35	27	28	22
No	35	52	65	54	66	45	53	68
Unknown	5	0	9	0	0	2	0	2
Age								
11	n/a	n/a	n/a	n/a	n/a	n/a	3	5
12	n/a	n/a	n/a	n/a	n/a	15	12	12
13	15	17	20	14	9	7	18	20
14	17	17	26	15	18	20	19	15
15	18	27	24	28	27	18	19	20
16	20	17	15	25	29	17	10	20
17	9	19	16	15	18	n/a	n/a	n/a
TOTAL	**79**	**97**	**101**	**97**	**101**	**77**	**81**	**92**

Youth Participation

CHIVA Youth Committee

CHIVA established a youth committee in 2010. Twelve committee members, living with HIV, work closely with the CHIVA staff and executive teams. The youth committee are involved in camp planning and annual camp themes. The importance of camp is presented by quotes from youth committee members below.

> *"C - comfort A- acceptance M- measurement P- personality … Camp, a four letter word that changes life experiences … Camp is a place of home providing comfort, surrounding yourself with people who know what it feels like to be rejected by the world and have only your own comfort. …………Camp is not just about surrounding yourself with other people but finding who you are and accepting that one little part of you does not define you.*
>
> *"To me, camp is important because it's a place where I can talk about HIV without getting judged, [….] where I learn more about HIV and about myself […] a place where you find how to be strong, and never let anything put you down*

The CHIVA youth committee attend camp each year and hold consultations with camp attendees. These consultations ensure that the work of the youth committee is led by current needs and priorities of children and young people with HIV. This in turn shapes and informs development of future CHIVA initiatives and future camps.

Camp leader programme

The camp leader programme provides peer mentor roles at camp for 12 young people with HIV aged 18-24, many of whom were previous camp attendees. Camp leaders attend a four day accredited residential course on youth work approaches in preparation for their role at camp. In addition to peer mentoring, camp leaders also support workshop facilitation, give testimonies on personal experiences and how difficulties have been overcome. They lead on the delivery of particular aspects of camp. Following on from taking camp leader roles many young adults continue to become key workers who have increased responsibility for the care and support provided to camp attendees.

This model of participation and engagement of previous camp attendees ensures the intervention is user lead, and structured to provide ongoing opportunities for the participation of young people and young adults with HIV in its delivery.

Measuring Impact

An evaluation is completed by young people following each camp. In 2015, a more comprehensive evaluation of F2B was carried out to measure the impact of camp in relation to the knowledge, self-esteem, confidence and the support aims of the camp [6,7]. A part of this evaluation consisted of 19 semi-structured interviews, conducted by a member of the evaluation team with 11 camp attendees aged 12-16 years. These took place at two time points, roughly six weeks after camp and at a six-month follow-up. Thematic analysis was conducted on the qualitative data collected and a paper on these findings has been published earlier this year [7]. A variety of quotes from evaluations and interviews, which evidence some of the significant perceived benefits of camp, are presented in this paper.

Benefits of Camp

Reducing isolation

Reported changes to campers' self-image and behaviours are largely a result of meeting new people and gaining new knowledge in HIV-focused workshops. It is important to emphasise that the large size of this group is fundamental to the measured impact of camp. F2B is the largest psychosocial intervention of its kind in the UK and this unique feature plays a role in the positive outcomes observed in those who attend. The number of young people (92 in 2017) living with HIV who are able to meet in the same place over an extended period of time allows for increased diversity, experiences, and perspectives to which camp attendees are exposed.

Some young people live in geographically remote locations and lack the opportunity to interact with peers living with HIV in their age group at regular intervals throughout the year. Over half of camp attendees have no access to any support outside of their clinical care, highlighting the importance of camp as an intervention.

Campers reported a decreased sense of isolation and the ability to have conversations with other young people that wouldn't happen in their home environment. Additionally, the large number of campers in attendance means there is an increased chance of deep friendships being formed.

> *"I've kinda been quite secluded at home with my school but I, I loved how much fun people had and how much we just talked about normal things and we could joke about ourselves. Now I'm more confident, more at ease with myself mentally and physically and less alone."*
>
> *"It felt natural to be able to talk about things like that cause I'd like to bring it up with my other friends who aren't HIV positive but they'd be trying to react appropriately… actually sometimes you just want to talk, you're not trying to get a reaction and that's, that was much easier at camp cause we'd just talk, we wouldn't have to say…"*
>
> *"You know like, with your people here, people in college and people in camp… it's a different connection if you know what I mean. I want to be a part of that connection if that makes sense."*

A change of perspective

The large number people at camp also reveals different perspectives and varied experiences, which may not be brought to light in a smaller clinic or community organisation.

> *"It was a good experience. It was a good chance to see what other people thought about it so it was kind of an eye-opener"*
>
> *"Yeah a lot of people did, shared and those people that had worse situations than I did […] It made me feel like maybe it's not so bad for me."*
>
> *"I learned how other people felt about HIV and how different it was to my view. For me, it's never really had that much of an effect on me before. The people, when they said they found out, it really kind of broke them and they felt like it was a huge part of their life. Maybe some people, saw it 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."*

Personal growth and communication

The environment at camp fosters open discussion and increases the chance that campers will be able to connect with the most appropriate person for the particular issue they are interested in dealing with. This could mean either guidance from an older camper or staff member, or sharing experiences with someone their own age.

> *"Well I think the year before I'd just found out that I was HIV positive and I thought this can't happen, I can't … then I went to this place and there were so many people who seemed happy."*

> *"I think I have quite a good relationship with my doctor so I'd often talk to her about things but if it's more casual and less medical then I would talk to friends from camp or hope to talk to them."*

> *"I'm glad. I was expecting it to just be like a fun time and…I'd have some more friends but it has actually changed me cause I don't know, I'm more confident and happier in myself. Yeah, so I'm really glad it happened."*

Facilitating ease of access to information

Camp provides a unique environment where young people can easily access accurate and current information about HIV from a range of sources.

> *"If you have questions you can just ask them. […] If I had questions, I'd talk to one of my friends or one of the workers or leaders cause the similar age groups, there wasn't a proper order. I felt comfortable cause I have the conditions. "*

> *"I hadn't been interested but being this age and wanting to know about my college and work and relationships and stuff, I'm more interested in the law and I found out that I have a lot more rights than I thought I did."*

The friendships made at camp also allow young people to have conversations in relation to their HIV status and create a social support network that can continue over social media once they return home.

> *"Life has been good, I feel like it's been easier for me to communicate with other people and make friends more easily."*

> *"Camp is important cause you get to take away two things from it: Courage and Friendship."*

> *"I feel happy. When I'm there it makes me feel open cause with my friends, when they talk about HIV, I have to keep some things […] quiet cause if I say too much they'll ask how I know things."*

> *"Like we've been texting each other ever since, like we'd stay up until midnight or one o'clock in the morning having midnight chats about life, relationships, HIV and all that stuff."*

It is known that HIV communication in families is often difficult and young people report limited opportunities for supportive conversations around HIV within their family unit . Camp allows young people to develop their own relationship with their HIV, which does not simply mirror what they may have experienced in their family context. We know for many families talking about HIV at home can be difficult and CHIVA aim to support young people to feel confident and comfortable talking about their HIV.

Conclusions

The psychosocial benefits of F2B have been shown and must be continually highlighted, not only to paediatric and adult HIV clinicians but also to other stakeholders looking to provide interventions for young people living with HIV or other chronic conditions. The wider evaluation report from 2015 presents recommendations on how camp can be improved and might prove useful for those interesting in setting up similar camps.

The young people who attend camp often experience a range of HIV related social and psychological stressors alongside the complexities of managing life-long HIV medical treatment and care. F2B fosters knowledge and understanding, skills, confidence and resilience needed in this group of young people. The ability to interact with a large number of peers who can relate to shared experiences or provide different perspectives is crucial as young people learn to cope with their HIV status. This influences their lives more broadly by developing their capacity to cultivate and maintain personal relationships whilst enhancing their emotional well-being.

As young people age and transition to adult services it is important for medical professionals who will assume their adult care to have a sense of their lived experiences, which could drastically differ from people who did not acquire HIV perinatally. In the current climate of diminishing HIV community support, interventions like F2B become more critical to ensuring the well-being of young people who are growing up with HIV and preparing them for adult care.

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