

A longitudinal evaluation of an intensive residential intervention (camp) for 12-16 year olds living with HIV in the UK: Evidence of psychological change maintained at six month follow-up

BRIEF REPORT

Running Head: Evaluation of residential support camp intervention for adolescents

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Abstract

There are large numbers of young people with HIV globally, the majority of whom have perinatally acquired HIV (PAH). Despite evidence of lower levels of wellbeing in young people with PAH compared to HIV unaffected peers, there are few psychosocial interventions for this population. Residential interventions (camps) for young people with HIV have the potential for enhancing well-being and improving HIV-related outcomes. There have not been any quantitative evaluations of camps for young people with HIV. This study evaluated a week-long intensive residential intervention for 12-16 year olds living with HIV in the UK. A quantitative repeated measures design was used. Forty nine participants completed assessments before and immediately after the intervention (post-intervention) and at six month follow-up (73% retention rate; 28 (57%) female; median age 14 years, IQR 13-15 years). Self-report measures suggested improvements in both HIV knowledge and pro HIV disclosure affect and cognitions post-intervention, maintained at six month follow-up. There were improvements in antiretroviral adherence beliefs from baseline to six month follow-up, and in self-perception from baseline to post-intervention. These changes are important in their own right but may also be mediators of other outcomes such as increased ART adherence and reduced onward HIV transmission risk. The study suggests that brief residential interventions have the potential to facilitate sustained change in psychological outcomes. Research and practice implications are outlined.

Key words: Adolescence; residential; camp; psychosocial; intervention

Introduction

There are approximately two million 10-19 year olds with HIV, many with perinatally acquired HIV (PAH) (UNAIDS, 2013). Adolescents with PAH face sexual health, well-being and antiretroviral (ART) adherence challenges (Kim, Gerver, Fidler, & Ward, 2014; Mellins & Malee, 2013). Some difficulties, such as feelings of isolation, may be salient where HIV prevalence is low, for example the UK (PHE, 2016).

There are few reported psychosocial interventions for adolescents with HIV (Skeen et al., 2017). Offering *residential* interventions (camps) may enhance well-being, self-esteem, ART adherence and HIV knowledge. There is evidence in other chronic conditions of increased self-esteem after attending camps (Odar, Canter, & Roberts, 2013). Only qualitative methods have been used in HIV camp evaluations (Gillard, Witt, & Watts, 2011). Given the lack of quantitative (and longitudinal) data, we assessed whether there were changes in post-intervention and six month follow-up camp outcomes compared to baseline for UK 12 to 16 year-olds with HIV.

Methods

A single group repeated measures design was used, with assessments before, immediately after (post-intervention) and six months after camp. All seventy seven attendees of a UK camp for 12 to 16 year olds with HIV were approached (29 attended previously, 32 currently receiving HIV support). Sixty seven participated, 49 at all time points (Figure 1).

Figure 1

See Table I for demographic/clinical information.

Table I

The Children's HIV Association (CHIVA), provided the intervention (4th - 8th August 2015 inclusive). The camp (offered to all UK 12-16 year olds with HIV) aimed to facilitate peer friendships, increase HIV knowledge and understanding, and improve confidence/self-esteem. Individual emotional support; participatory HIV knowledge and understanding, and sexual health group workshops; creative/performing arts; and sports were provided. Professional staff included a social worker, child participation experts, and a nurse. A volunteer team comprised camp leaders (peers aged 18-24 with HIV) and key workers.

Measures

Psychological variables

HIV Knowledge

A 19-item measure used items mainly sourced from other measures (Aaro et al., 2011), for example, "A woman can transmit HIV to her child through her breast milk". Responses were 'true', 'false' or 'don't know' ($\alpha = 0.76$ baseline; 0.65 post intervention; 0.79 follow-up).

Antiretroviral (ART) adherence cognitions

This 13-item measure used items sourced from an existing measure (Horvath, Smolenski, & Amico, 2014) including: "I am confident I can take my HIV medication whatever else I'm doing". Responses were on a five-point scale from "strongly disagree" to "strongly agree" ($\alpha = 0.77$ baseline; 0.77 post intervention; 0.79 follow-up). Higher scores reflected more pro-ART cognitions.

HIV disclosure cognitions and affect

The 18-item *Adolescent HIV Disclosure Cognition and Affect Scale* (Evangeli, 2017) assesses beliefs and feelings about sharing one's status. Examples item include, "It will affect my relationship with them" and "I am afraid to tell other people that I have HIV." Responses

were on a five-point scale from “*strongly disagree*” to “*strongly agree*”. Higher scores reflected more pro-disclosure affect and cognitions ($\alpha = 0.71$ baseline; 0.79 post intervention; 0.81 follow up). An additional item assessed disclosure intention over the next six months.

HIV communication beliefs

This seven-item questionnaire assesses beliefs about HIV communication (Evangelini, in press), for example, “*It makes me feel better*”. Responses were on a five-point scale from “*strongly disagree*” to “*strongly agree*” ($\alpha = 0.80$ baseline; 0.78 post intervention; 0.64 at follow up). Higher scores reflected more positive HIV communication beliefs. An additional item assessed HIV communication intention in the next six months

Self-perception

The five item self-perception subscale from the KIDSCREEN was used (Ravens-Sieberer et al., 2005) (e.g. “*Have you been happy with the way you are?*”). Responses were on a five-point scale (“*never*” to “*always*”). Higher scores reflected more positive self-perception in the last week ($\alpha = 0.76$ baseline; 0.72 post intervention; 0.85 follow up).

Behavioural variables

HIV disclosure was assessed at baseline and follow-up, “*In the last 6 months, have you told anyone you are HIV+ who didn’t know before?*” HIV communication was assessed at baseline and follow-up: “*In the last 6 months, have you spoken to anyone about your HIV (not part of your clinic or working for an HIV organisation)?*”, and, “*How often do you talk about HIV with someone who is not at the clinic or working for an HIV organisation?*” (5 point scale from *never* to *daily*)

Clinical/demographic information was elicited at baseline and follow-up, and also obtained from the UK Collaborative HIV Paediatric Study (CHIPS).

Ethics

Ethical approval was granted from Royal Holloway University of London Psychology Department Ethics Committee (2015/052). Approval to use CHIPS data was provided, with participant identifiers allowing anonymous data linkage. Written assent/consent was sought from attendees, parental consent for attendees under 16 years.

Procedure

Measures were administered in paper/pencil form at baseline and post-intervention and both online and paper/pencil at follow-up. Staff were available to assist participants if required. Participants completing follow-up questionnaires received a £10 Amazon voucher.

Data Analyses

Independent t tests and chi-squared tests compared those retained and not. One way repeated measures ANOVA, paired t tests and McNemar's tests compared time points. Post-hoc pairwise comparisons with Bonferroni corrections followed up ANOVAs. Two tailed tests were used with significance at 0.05.

Results

There was no evidence that those completing follow up measures differed on psychological variables at baseline compared with those who did not (all p values >0.2). See Table II for psychological scores.

Table II

Psychological variables

HIV knowledge scores differed, $F(2, 86) = 11.76$, $p < 0.001$. Scores improved from baseline to post-intervention ($p < 0.001$), and follow-up ($p = 0.003$), with no change between the latter points ($p = 1.00$).

ART adherence cognition scores differed, $F(1.81, 79.67) = 3.85$, $p = 0.03$, with higher scores from baseline to follow-up ($p = 0.004$), but not from baseline to post intervention ($p = 0.36$), or post-intervention to follow-up ($p = 1.00$).

HIV disclosure cognitions and affect scores differed, $F(2, 90) = 13.68$, $p < 0.001$, increasing from baseline to post-intervention ($p < 0.001$) and follow-up ($p = 0.002$), with no difference from post-intervention to follow-up ($p = 0.69$). HIV disclosure intention scores did not differ, $F(2, 90) = 0.37$, $p = 0.69$.

HIV communication belief scores differed, $F(2, 92) = 3.17$, $p = 0.05$, with scores reducing from post-intervention to follow-up ($p = 0.04$), and no evidence of differences between baseline and either post-intervention ($p = 0.38$) or follow-up ($p = 1.00$). Communication intention scores did not differ, $F(2, 92) = 2.04$, $p = 0.14$.

Self-perception scores did not differ, $F(2, 80) = 2.98$, $p = 0.06$. Scores did, however, increase from baseline to post intervention ($p = 0.03$) but not to follow-up ($p = 0.35$). There was no differences between post-intervention and follow-up ($p = 1.00$)

Behavioural variables

Twelve participants had shared their status with someone new in the previous six months at baseline and six at follow-up. There was no evidence of change in the disclosure rate ($p = 0.11$).

Twenty two participants had communicated about HIV at baseline and fifteen at follow-up. There was no evidence of change in HIV communication presence (yes/no) in the last six months ($p=0.17$). There was no differences in HIV communication frequency from pre-intervention (mean 2.14, sd 1.22) to follow-up (mean 2.05, sd 1.25), $t(41) = 0.39$, $p=0.70$.

Discussion

HIV knowledge and HIV disclosure cognitions and affect scores increases were maintained after camp. These changes may mediate change in other important outcomes (e.g., ART adherence). The HIV knowledge findings could be explained by the lengthy HIV information session, repeating information in multiple workshops, using interactive methods and a more relaxed learning environment than clinic. Increases in pro HIV disclosure cognitions and affect may have occurred due to role play and sharing of disclosure experiences both within and outside of workshops. Confidence in sharing one's status, and more positivity/less concern about disclosure outcomes, did not translate into intending to or sharing one's status more at follow-up, however. This might require a more intensive intervention.

The pattern of ART cognition scores may have been due to the ongoing focus on ART adherence in clinics rather than due to camp. There was no change in HIV communication behaviour, perhaps as this is also dependent on the perceived beliefs and behaviour of others (e.g., families). It may be helpful to communicate with families about camp content to facilitate ongoing familial HIV communication.

Significant findings were revealed in domains consistent with the intervention's focus, despite the small sample. The absence of a comparison group makes it difficult to attribute changes to the intervention, however. Effects may have been strengthened or maintained by post-camp processes occurring *due* to the camp (e.g., ongoing connections between attendees

facilitated by social media (Lut, Evangelini, & Ely, 2017)). A number of measures used (despite piloting and carrying out Principal Components Analysis) had unproven reliability and validity. Response/retention rates were good, and there was no evidence of selection bias. Participants' age and birth region were representative of UK adolescents with HIV (CHIPS, 2015).

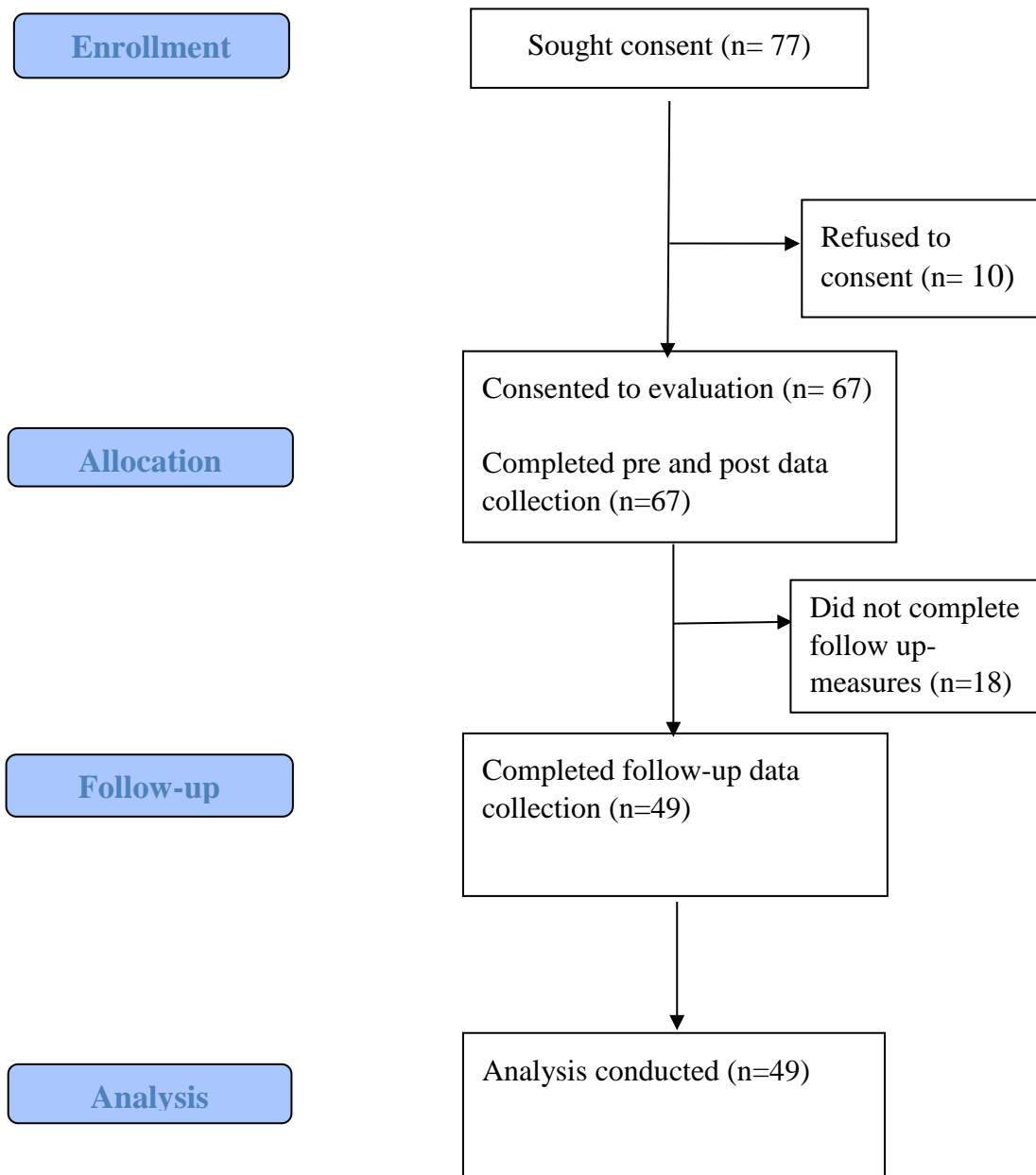
Future studies should recruit comparison groups (e.g., adolescents receiving psychosocial support in clinics/in the community). Assessing potential mediators of change, for example, increased social support and reduced internalised stigma, should be undertaken. Relevant variables (e.g., viral load, clinic attendance, HIV disclosure) should be measured reliably and validly. Strategies could be developed to maintain changes not sustained at follow-up (e.g. self-perception). This may involve considering booster sessions and sustainable peer support.

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Figure 1: Study Flow Diagram



		Frequency (%)
Gender	Female	28 (57)
	Male	21 (43)
Age (in years)	Median	14
	IQR	13-15
Region of birth	Africa	27 (55)
	UK/Europe	20 (41)
	Asia	2 (4)
Age at Naming/ Paediatric Disclosure (in years)	<10	13 (27)
	10-12	28 (57)
	>12	5 (10)
	Not specified	3 (6)
Ethnicity (n=47)	Black African	34 (72)
	Mixed	6 (13)
	White	5 (11)
	Other	2 (4)
CD4 count (mm ³ , n=44)	Median	690
	IQR	511-998.5
Viral Load (copies/mL, n=42)	<50	34 (81)
	≥50	8 (19)
Antiretroviral regimen (n=41)	Nucleoside Reverse Transcriptase Inhibitors (NRTIs) + Protease Inhibitor	18 (44)
	NRTIs + Nevirapine	11 (27)
	NRTIs + Efavirenz	10 (24)
	Other	2 (5)

Table 1: Sample demographic and clinical characteristics (n=49)

	Baseline (mean/sd)	Immediate post- intervention (mean/sd)	Six month follow-up (mean/sd)	P value
HIV knowledge¹	31.94 (3.12)	33.57(3.37)	33.26 (3.29)	<0.001
ART adherence cognitions²	48.80 (7.68)	50.52 (6.88)	51.69 (7.70)	0.03
HIV disclosure affect and cognitions³	55.85 (8.27)	61.28 (8.85)	60.09 (9.51)	<0.001
HIV disclosure intention³	2.68 (1.20)	2.79 (1.29)	2.59 (1.13)	0.69
HIV communication beliefs⁴	25.84 (4.82)	26.99 (4.74)	25.06 (4.51)	0.05
HIV communication intention⁴	2.87 (1.26)	2.83 (1.36)	2.47 (1.28)	0.14
Self-perception⁵	17.87 (5.07)	19.36 (4.31)	18.93 (5.29)	0.06

¹n=44; ²n=45; ³n=46; ⁴n=47; ⁵n=41

Table 2: Psychological Measures for participants retained in the study