Evaluation of CHIVA Support Camp (Freedom 2 Be) 2015

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Declaration of Interest

<table>
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<tr>
<th>Speaker Name</th>
<th>Statement</th>
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<td>Dr. Michael Evangeli</td>
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Date: May 2016
• Evidence of increased self-esteem after attending residential interventions for youth with medical conditions (Odar et al, 2013).

• Most evaluations of residential interventions for young people living with HIV have been qualitative with limited follow-up (e.g., Gillard et al, 2011).

• Existing evaluations of CHIVA Support Camp have suggested its benefits.

• Evaluating complex interventions without (or with!) a control group is challenging.
Aims

To measure changes in psychological, behavioural and clinical outcomes from before F2B to after F2B.

To capture the experience and perceived impact of the Camp for Camp attendees, Camp staff, clinic staff and parents.
Methods - design

Sub study 1

- Quantitative repeated measures uncontrolled design: pre/post/6 month follow-up
- Pre and post: n=67: 87% response rate
- Follow-up: n=49: 73% of those who consented, 64% of attendees
- Quantitative repeated measures uncontrolled design and possible quasi experimental design
- Comparing clinical outcomes pre and post Camp for Camp attendees (1 year pre and 1 year post).
- Comparing attendees and CHIPS cohort on clinical outcomes (1 year pre and 1 year post).
- NB Data not yet available for this component
Methods - design

Sub study 2

- Semi-structured interviews
- Post Camp: Camp attendees (n=11), staff (n=6). Stratified sampling by age and staff role
- Follow-up of those who participated in Post Camp interviews: Camp attendees (n=8), parents/carers (n=7), clinic staff (n=9)
- Post Camp Surveys
- Camp attendees (n=64), staff (n=29).
- Workshop Surveys
- Camp attendees
Methods - procedure

- University Ethical approval
- Parental opt out consent; Camp attendee written assent/consent
- Pre-Camp: self-report measures on first day of Camp
- Mid-Camp: feedback forms after each workshop
- Post-Camp: self-report measures and surveys completed on last day of Camp
- 1-2 months after Camp: semi-structured interviews
- 6 months – self-report measures
- 7-8 months – semi-structured interviews
- 12 months – clinical data
Methods – measures

- Use of pre-existing measures where available, and questionnaires developed for this evaluation (sourcing questions from literature, generating questions, piloting, factor analysis).

- New multi item measures of HIV knowledge, ART adherence cognitions, HIV disclosure cognitions and affect, HIV communication cognitions

- Existing multi item measures of HIV anticipated and enacted stigma, self-perception, QoL, general health

- Frequency counts of ART adherence, HIV disclosure x recipient, HIV communication x recipient.

- Single item likert scales on HIV disclosure and communication intention and communication frequency

- Open ended questions on HIV disclosure planning

- Questions on support and changes in medication and life at follow-up
Methods – surveys and interviews

Surveys

• Ratings of what learned and enjoyed
• Suggestions for improvements

Interview guides

• Open questions about Camp experience and post-Camp impact
Results – self-report measures

Sub study 1. NB only pre-post Camp data fully analysed + sample size smaller at follow-up/limited power

- HIV knowledge – positive change (p<0.001). Effect appears to be maintained at follow up. No evidence of age or gender moderation.
- ART adherence cognitions – ns (p=0.15)
- HIV disclosure cognitions – positive change (p<0.001). Effect appears to be maintained at follow up. No evidence of age or gender moderation.
- HIV communication cognitions – positive change (p=0.05). Effect does not appear to be maintained.
- HIV anticipated and enacted stigma – ns (p=0.79)
- Self-perception - positive change (p=0.01). Effect does not appear to be maintained.
- QoL - ns (p=0.12)
- General health – ns (p=0.79)
Results – overall experience

Sub study 2 - Camp attendees and Staff

• Very positive overall experiences

• “Well I don’t want to change anything about camp, that’s the thing. Camp is such a lovely thing to do and it’s a unique experience.” [Camp attendee]

• “She was very hyped up about it all and enthusiastic about her experience.” [Parent]
Results – inclusion of 12 year-olds and HIV disclosure

• “Like at first I was kind of like oh that’s a bit young but then if somebody’s told at 10 and then don’t go to camp until 13... that’s 3 years to kind of deal with something on your own.” [Staff]

• “…most successful workshop was when she shared her experiences of disclosure. Now she wasn’t ready to do that previously, cause she’s on her own journey but you could hear a pin drop in those workshops.” [Staff]
Results – Post-Camp and Follow-up

Adherence

“Every time I took them I felt like it was a reminder like that I had HIV but then at Camp it was like not letting it define who you are and just being you and in life. I was like “yeah I’m gonna do that” and ever since Camp I’ve been taking my medication.” [Camp attendee]

Communication

“I talked to everyone! Like right now, as soon as camp finished, there was a group that was made and there were like 40 of us in it. [...] We’re so tight.” [Camp attendee]

“I feel like it’s been easier for me to communicate with other people and make friends more easily.” [Camp attendee]
Confidence

“[Camp] did change a lot for me because before I was like so scared [...] of what people would think but [...] it’s hard not to tell someone and really talk about it but now I feel I can be open.” [Camp attendee]

“He’s been a lot more chatty and relaxed [...] Definitely more confident when he’s come to clinic.” [Clinic staff]

“He needed it because he doesn’t mix with anyone his own peer group. That’s got him out of himself.” [Parent]
Acknowledgements

• The young people, carers, Camp staff and Clinic staff who completed the evaluation measures and interviews.

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