

The HIV Empowering Adults' Decisions to Share – UK/Uganda Project (HEADS-UP): A Qualitative Analysis of Interviews with Participants and Therapists.

Aoife O'Keeffe¹, Joseph Price², Georgina Gnan², Janet Seeley¹, Sarah Fidler³, Victor Musiime^{4,5}, Annette Uwizera⁵, Graham Frize⁶, Caroline Foster⁷, Michael Evangeli²

¹ London School of Hygiene and Tropical Medicine, London, UK, ² Royal Holloway University of London, ³ Imperial College London, UK, ⁴ Makerere University, Kampala, Uganda, ⁵ Joint Clinical Research Centre, Lubowa, Uganda, ⁶ Central and Northwest London NHS Foundation Trust, London, UK, ⁷ Imperial College NHS Healthcare Trust, London, UK

Background

- Young adults living with perinatally acquired HIV (PAH) face many challenges, including adhering to antiretroviral therapy (ART), managing onward HIV transmission risks, and potentially complex family dynamics in an atmosphere of HIV stigma and secrecy.
- Sharing one's HIV status with others (onward HIV disclosure) may assist with these challenges.
- Rates of HIV status sharing are, however, low.
- There are no existing interventions focused on supporting decision-making about sharing one's HIV status for young adults born with HIV.
- This study developed such an intervention in the HEADS-UP study.
- We assessed the experience of intervention participants and therapists in the UK and Uganda through findings from in-depth interviews with participants and therapists.

Key Themes of the Qualitative Interviews

Five Key themes were identified in the qualitative interviews that were conducted in the UK and Uganda:

- (A) Benefits of Peer Support
- (B) Educational Impact
- (C) Feelings Towards HIV Status Disclosure
- (D) Study Process
 - (i) Positive
 - (ii) Negative
- (E) Application of Skills and Knowledge after the Intervention

Results

- All participants reported being satisfied with the study.
- The main theme that arose was the benefits of peer support.
- The main perceived strength of the study was that it was well organized and designed.
- The main reported limitations were the lack of follow up support from therapists and the length of study questionnaires.
- Therapists appreciated the flexible nature of the intervention, with participants able to revisit topics and learn from a range of individuals.
- The main limitation according to therapists was the large amount of information to deliver in each session.
- When asked about sharing their HIV status, participants chose to, or planned to, share their HIV status with a wide range of recipients (i.e., friends, family and partners)
- Many of the participants mentioned that there was a further need for support groups for young adults living with PAH

Conclusions

- The findings suggest that the intervention is acceptable for participants living with PAH in different cultural settings.
- Age-appropriate support services are crucial for this group as they reach young adulthood.
- Further research is needed to explore ways of how to empower and support young people living with PAH to share their HIV status with others.

Methods

- The study used a randomised parallel group feasibility design.
- Participants were randomly assigned to an intervention or a standard of care condition using block randomisation.
- Participants were living with PAH, aged between 18 and 29 in the UK, and 18 and 25 in Uganda.
- The intervention was delivered by one professional and one peer worker.
- Semi-structured interviews were conducted with 24 individuals (13 Uganda, 11 UK; 19 study participants (10 intervention, 9 SOC), 5 therapists; 8 male, 16 female).
- The interviews took place immediately after the intervention and at six month follow-up, with participants from both the intervention and SOC conditions.
- Thematic analysis was used to analyse the data.

Example Quotes from Participant and Therapist Interviews

"the intervention made me realize that the situation I was in I wasn't facing it alone, the intervention gave me a chance to meet my fellow youth and we shared about our problems ...It relieved me from a burden of thinking that I was passing through a situation alone. So, the intervention affected me positively." (Intervention group, Uganda)

"the facilitators were knowledgeable about the intervention... at the end of the session we would have understood it all. They were also free to answer questions about what we have not understood...we got on very well." (Intervention group, Uganda)

"I feel like we're all living like the same life just in different variations. When you find your group of people it's like...how can I put it; my peers are all experiencing the same thing just differently, it was interesting how the study brought that to life." (Intervention group, UK)

"I would say it empowered me to move my timeline forward. For me personally it made me realise that sometimes I- over preparation is a thing and it doesn't- not everything has to be incredibly rehearsed ...it reconfirmed... it was more like you can do this, you actually have it in you, stop messing around, like there's no there's no time like the present." (Intervention group, UK)

"I personally feel like overall people really did enjoy doing it. I think they really gained a lot of knowledge and confidence, you know, like being part of the study and I think what also really helped is that there were loads of different experiences within the group which was really nice as well because it was like somewhere you shared experiences". (Therapist, UK)

"There were instances whereby through different experience sharing, they would also share their feelings and you would be in position of course to address them (yeah) and counsel them even in the training to ensure that they gain the confidence and momentum to manage." (Therapist, Uganda)

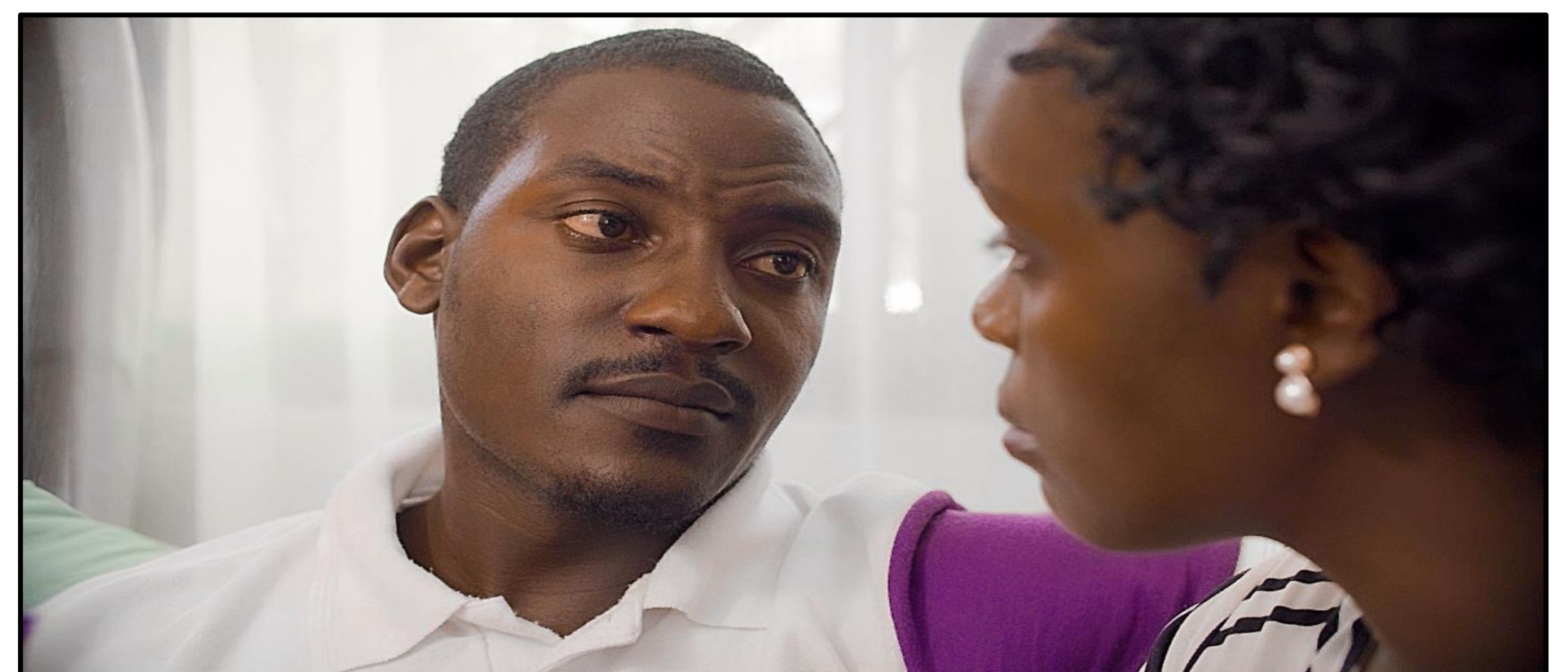


Image from dramatized film used in the intervention. Picture used with consent

Acknowledgements

We are so grateful to all the young people who took part in this study. Thank you! This would not have been possible without them. The authors would like to thank ViiV Healthcare UK for funding the study. Particular thanks to then ongoing support of Chris Stainsby and Serufusa Sekidde from ViiV Healthcare UK

