THE HIV EMPOWERING ADULTS' DECISIONS TO SHARE – UK/UGANDA PROJECT (HEADS-UP):

Quantitative outcomes

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HEADS-UP

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ROYAL HOLLOWAY UNIVERSITY OF LONDON

ViiV Healthcare

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LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Imperial College Healthcare NHS NHS Trust

THE HIV EMPOWERING ADULTS' DECISIONS TO SHARE – UK/UGANDA PROJECT (HEADS-UP)

A study in which we developed and tested the feasibility of an HIV sharing intervention for young people who were born with HIV in the UK and Uganda

- 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 a context 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 in this population.
- There is a lack of sharing guidance to support young people with PAH or professionals working with this population, so we developed a programme to support young people with sharing their status.

PARTICIPATORY APPROACHES

Phase 1 - Intervention development

ADVISORY GROUP

HIV+ Young people, charity representatives, policy makers, health professionals & academics,

SEMI-STRUCTURED INTERVIEWS

HIV+ Young people, family members, friends & partners

INTERVENTION DRAFT DEVELOPMENT

By the research team

FEEDBACK INTERVIEWS

Setting, wording, activities, films

ADVISORY GROUP 2

Phase 2 - Feasibility testing

BEHAVIOURAL INTERVENTION

4 online (UK) / in person (Uganda) group sessions (or comparison group - standard of care)

SESSION EVALUATION FORM

After each session

IN DEPTH FEEDBACK INTERVIEWS

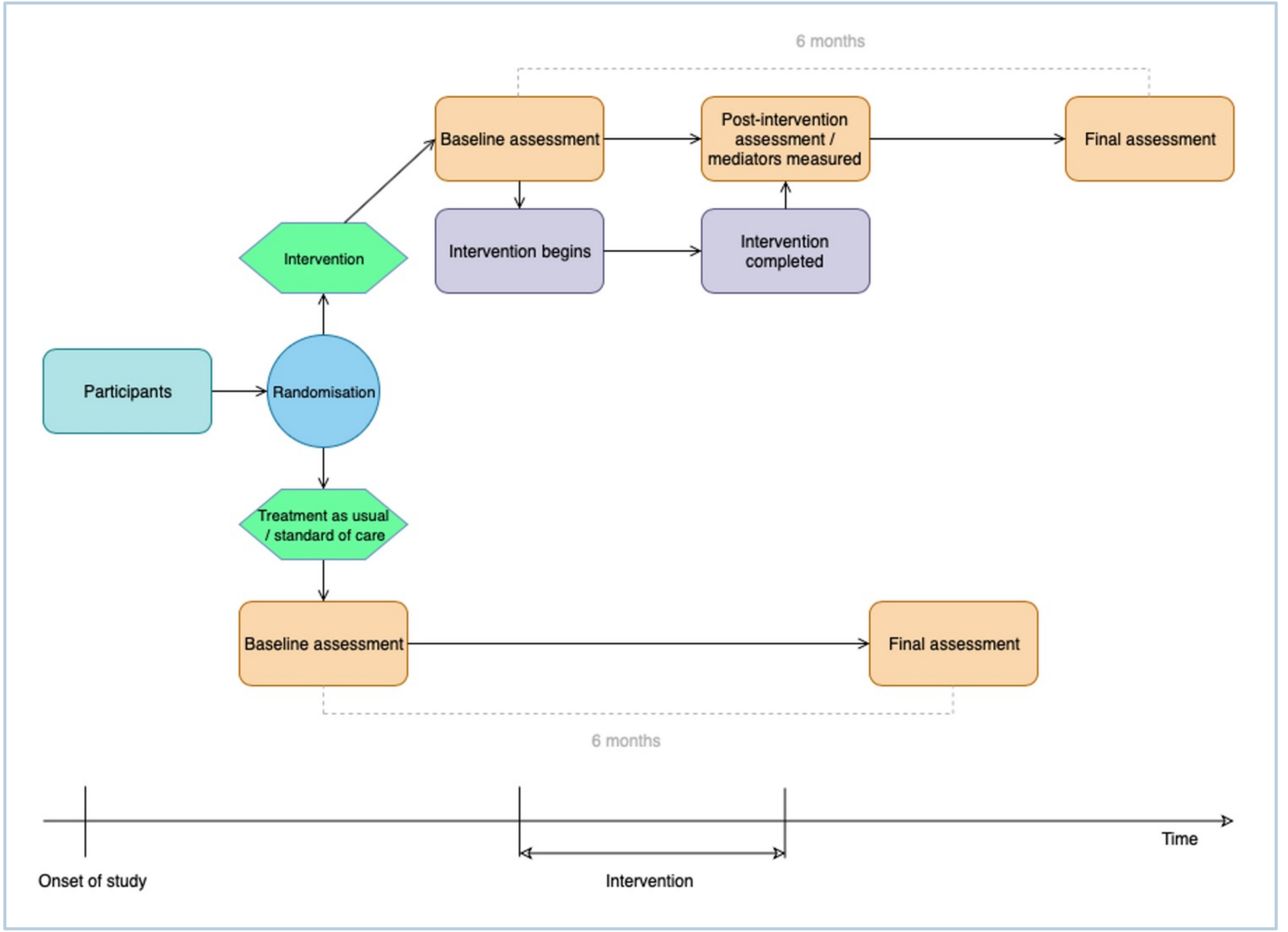
Post intervention and 6 month follow up

PEER SUPPORT WORKER / “THERAPIST”

METHODS

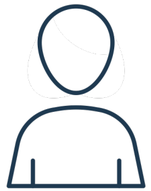
The study used a randomised parallel group feasibility design.

- Participants were randomly assigned to an intervention or a standard of care condition using block randomisation.
- Assessments were carried out at: (1) Pre-intervention /baseline; (2) Post-intervention (intervention group only); and (3) Six-month follow-up.



Participants

- Participants were living with PAH

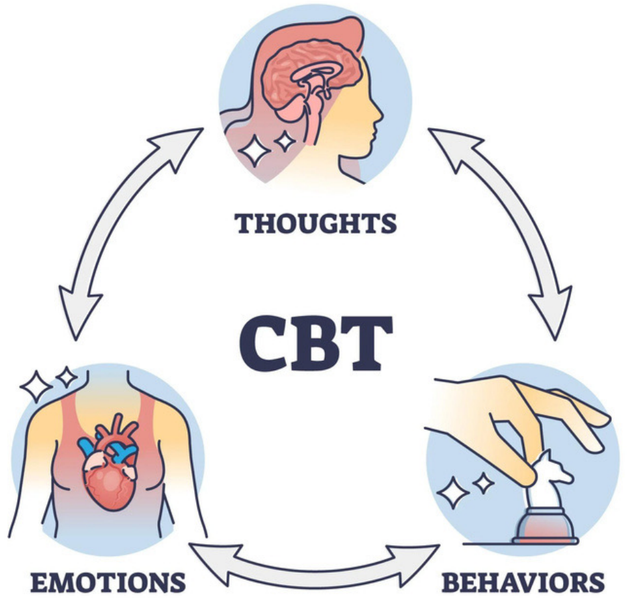


aged 18-29
in the UK

aged 18-25
in the Uganda

Intervention

- The intervention used strategies from motivational interviewing and cognitive behaviour therapy



Intervention Components

SESSION 1 *(GROUP)*

- GROUND RULES
- LIVING WITH HIV
- WHAT DO I NEED TO KNOW TO BE READY TO SHARE?
- WHAT IS IMPORTANT TO ME?

SESSION 2 *(GROUP)*

- HIV SHARING QUIZ
- REASONS TO SHARE & NOT TO SHARE
- ANXIETY ABOUT SHARING
- FILM: EXPERIENCES OF SHARING
- PERSONAL GUIDELINES ABOUT SHARING

SESSION 3 *(GROUP)*

- FILM: BECKY & JAMIE (UK) / JOHN & ROSE (UGANDA)
- IF YOU'VE DECIDED TO SHARE TO A PARTICULAR PERSON
- AFTER SHARING
- PRACTICING SHARING

SESSION 4 *(INDIVIDUAL)*

- PERSONAL SHARING GUIDELINES (USING A PROFORMA)
- HELPFUL RESOURCES

+6 MONTH FOLLOW UP SUPPORT

It consisted of four 90-minute sessions (3 group, 1 individual) with follow-up support to increase motivation and skills to share HIV status.

The intervention was delivered by one professional and one peer worker, with groups of up to eight, mixed gender.

Outcomes

Primary outcome measures:

- Recruitment, retention and acceptability

Secondary outcome measures (selected)

  - HIV disclosure behaviour, disclosure motivation & disclosure intention
  - Wellbeing
  - Social support
  - Hope

RESULTS

142 participants were recruited
- 94 Uganda, 48 UK;
- 89 female, 53 male
- Age: Mean (SD): 22.9 (2.6)

Of the 123 participants who responded, 17 (13.8%) had never shared their HIV status with anyone at baseline. Half of the participants have told 3 people or fewer in their lifetime.

Feasibility

At six-month follow-up:

- 92/94 (98%) participants were retained (i.e., completed measures) in Uganda, 25/48 (52%) in the UK.
- 59/71 (83%) participants were retained from the intervention condition, 58/71 (82%) participants were retained from the SOC condition.

Acceptability

- High levels of acceptability in both countries (Max score 84. Overall mean 73.18 (sd 6.04); Uganda mean 73.02 (sd 5.77); UK mean 73.90 (sd 7.49)).

Evaluation

- The total score on the session evaluation questionnaire was also very positive in both countries (Max score 56. Overall median 53 (IQR 49-55); Uganda median 52 (IQR 49-55); UK median 55 (IQR 52-56)).

- Participants rated the intervention as effective in helping with decisions about sharing (max score 7. mean 6.29, sd 0.85); likely to be helpful to others (max score 7. mean 6.23, sd 0.81); and stated that they intended to use the intervention in the future (max score 7. mean 6.29, sd 0.78).

RESULTS

Multivariate analysis

- There was a non-significant effect of intervention condition on both HIV disclosure cognitions and affect (i.e., disclosure motivation) p=0.08, and HIV disclosure intention, p=0.08.

- There was a significant effect of the intervention on well-being, p=0.005.

- Lifetime HIV disclosure at baseline was significantly positively associated with the following outcome variables at follow-up:
  - HIV disclosure cognitions and affect: p<0.001;
  - HIV disclosure intention: p=0.008.

- HIV disclosure intention (p=0.003) and well-being scores (p=0.002) were higher in the Uganda sample.

CONCLUSION

The intervention was acceptable and feasible, with strong evidence of a positive effect on well-being in young adults with PAH in Uganda and the UK.

- Although there was a lack of evidence that the intervention increased HIV status sharing motivation, the study may have been underpowered to detect a statistically significant effect at six months.

- These findings, along with findings suggesting that the intervention is acceptable and feasible, should support further efforts to develop effective interventions focused on HIV status sharing and wellbeing in young adults with PAH.

- The study is unique in its inclusion of young people from both high-income/low-prevalence and low-income/high-prevalence contexts.

- This study is the first to address important gaps in understandings of acceptable and feasible ways of delivering sharing support for young people with PAH.

HEADS-UP

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THANK YOU

FOR LISTENING

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