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“It empowered me to move my timeline forward”: first person thematically analysed accounts of a novel behavioural intervention to support status-sharing in young adults with perinatally acquired HIV in UK and Uganda

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ABSTRACT
Young adults living with perinatally acquired HIV (PAH) face many stressors. Sharing one's status may help with coping with these challenges but there are no rigorously evaluated interventions to support HIV status sharing in this population. The aim of this study was to explore the experiences of participants in a novel HIV status-sharing intervention guided by motivational interviewing. We used a cross-sectional, qualitative design. Ten young adults from Uganda (20–25 years; 6 female), nine from the UK (19–29 years; 7 female) and five therapists (2 UK; 3 Uganda) participated in individual semi-structured interviews. The data were analysed using thematic analysis. Seven theoretical themes were identified. Participants reported positive experiences of the intervention, a desire for more support and the importance of peer interaction. This study provides evidence for the acceptability of a novel HIV-sharing intervention for young adults with PAH. The intervention could inform HIV sharing guidance and clinical practice.

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HIV; perinatal HIV; disclosure; intervention; perinatal; qualitative

Introduction

Approximately, three and half million young people globally, aged between 15 and 24 years, are living with HIV, and a significant proportion of these have perinatally acquired HIV (PAH) (UNAIDS, 2021). There are an estimated 170,000 15–24-year-olds (regardless of route of infection) living with HIV in Uganda (Uganda AIDS Commission, 2022). Vertical transmission accounts for 22–25% of all HIV infections in the country (Uganda AIDS Commission, 2022). In the UK, there is a relatively small number of people living with PAH compared to Uganda (CHARS, 2024).

Young people with PAH share some similar challenges to those who acquire HIV behaviourally, for example, adhering to antiretroviral therapy and managing HIV stigma. Some stressors, however, relate specifically to perinatal HIV. Firstly, longstanding HIV infection acquired during infancy can cause severe morbidity extending into adult life (Henderson et al., 2024). Secondly, many young people with PAH have experienced loss due to parental and/or sibling illness or death (Mabasa et al., 2023; Mellins & Malee, 2013).

One of the challenges for young people living with HIV is sharing their status (onward HIV disclosure). Many barriers to HIV status-sharing exist, including the fear of rejection, humiliation and violence (Jopling et al., 2024; Zgambo et al., 2021). Sharing one's HIV status is uniquely challenging for young people with PAH because of concerns about revealing the HIV status of members of their family, often in the context of family secrecy (Hogwood et al., 2013).

There are several potential benefits to sharing one's HIV status. These include increased partner HIV testing, enhanced social support, increases in antiretroviral (ART) adherence and improved wellbeing (Bondarchuk et al., 2025; Nostlinger et al., 2015; Weintraub

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et al., 2017). In some cases (where the person living with HIV is not virally suppressed), HIV status sharing may reduce the risk of onward HIV transmission. The *need* to share with sexual partners, however, has lessened since the confirmation that ART-induced viral suppression prevents the risk of viral transmission to sexual partners (Rodger et al., 2019). Despite the potential benefits, globally, there are low rates of HIV status sharing among young people with PAH (Mugo et al., 2021; Weintraub et al., 2017).

Several multi-session HIV disclosure interventions have been developed for people living with HIV. Serovich and colleagues (Serovich et al., 2020) carried out an intervention in the United States that aimed to help people living with HIV (men who have sex with men, heterosexual men and women) with the decision-making process in sharing their HIV status with family members. Despite no significant intervention effect, the researchers found that the intervention improved wellbeing and decreased condomless anal intercourse (CAI) (Serovich et al., 2020). The Mahugu intervention in South Africa was developed to assist in HIV disclosure from mothers living with HIV to their HIV-negative infants exposed to HIV children (Rochat et al., 2017). The intervention was based in the home and led by a lay counsellor. The intervention showed success in increasing mothers' confidence in their ability to disclose, and increased disclosure rates compared to baseline (Rochat et al., 2017).

Evidence suggests that young people with HIV would like support in sharing their HIV status (Thoth et al., 2014). To our knowledge, there is no HIV status-sharing intervention specifically designed for young people with PAH, with a lack of guidance to support young people living with PAH (Evangeli & Foster, 2014). The World Health Organisation has called for work in this area, specifying the need for interventions to help adolescents disclose decision-making, support caregivers and train health-care providers (WHO, 2018).

We recently reported quantitative findings on HIV Empowering Adults' Decisions to Share – UK/Uganda Project (HEADS-UP), a study that aimed to develop and test the feasibility of a behavioural intervention to support HIV sharing decision-making in young people with PAH in Uganda and the UK (Evangeli, Gnan et al., 2024). The decision to carry out the intervention in both a high-income/low-prevalence setting (UK) and a low-income/high-prevalence setting (Uganda) was based on global evidence of low rates of HIV status sharing in young people with perinatally acquired HIV. Participants in the intervention condition reported higher levels of well-being at the six-month follow-up compared to those in the standard-of-care condition. In the current study, we report the experiences of young people and therapists who participated in HEADS-UP. This study aims to:

(1) Explore participants' and therapists' perceptions of the HEADS-UP study and the intervention.
(2) Determine the perceived strengths and limitations of the intervention.
(3) Generate recommendations for future HIV status-sharing interventions in this population.

Methods

Design and sampling

This study used a cross-sectional qualitative design. Inclusion criteria in both countries included participants from the HEADS-UP study who were living with PAH, receiving HIV care at study sites, had knowledge of their own HIV status and were aged 18–29 years in the UK and 18–25 years in Uganda. Participants were excluded if they had significant mental health issues, moderate to severe learning disabilities or were unable to communicate in English or Luganda. All HEADS-UP therapists were sampled. Participants from both the Intervention and Standard of Care (SOC) conditions in both countries were sampled using stratified random sampling (using Research Randomizer: https://www.randomizer.org/). The strata were condition (intervention and SOC) and time point (post intervention and 6-month follow-up).

HEADS-UP study

The HEADS-UP study took place in the UK and Uganda and has been described in full previously (Evangeli, Foster et al., 2020; Evangeli, Gnan et al., 2024). In the UK, participants were recruited from six inner-city NHS clinics in London, Birmingham and Manchester, which provide services for young people living with PAH, as well as from one UK-based HIV charity. In Uganda, participants were recruited from a not-for-profit organisation in Kampala, the capital city.

The UK NHS sites and the Uganda site had dedicated clinics for young people growing up with HIV who have previously been in paediatric care, with peer support and professional psychosocial support available in the Uganda site and in the majority of the UK NHS sites. In these clinics, young people could discuss HIV sharing with their multidisciplinary team, attend with their partner, and have access to a range of other services (e.g. HIV testing, PrEP, family planning, ART adherence support and condom provision). The standard of care in both countries, however, was for there to be no routine or structured psychosocial intervention to facilitate HIV sharing or sharing decision-making.

HEADS-UP used an individually randomised feasibility design. Participants were randomised to either the intervention or SOC arm. The follow-up was for six months.

The intervention consisted of four sessions: three group sessions, consisting of a maximum of eight participants, and one individual session. The group sessions were led by two therapists: one professional (psychosocial counsellor, clinical nurse specialist or social worker) and one peer worker (a young person living with perinatally acquired HIV). The content of the sessions was as follows:

- Session 1 – Engaging: ice breaker; intervention aims; ground rules; living with HIV; what do I need to know about HIV to be ready to share? What is important to me (values clarification exercise)?
- Session 2 – Focussing and Evoking: HIV sharing quiz; what reasons are there for not sharing or sharing an HIV status; anxiety about sharing; video – experiences of sharing; personal guidelines about sharing.
- Session 3 – Developing HIV Status Sharing Skills: Dramatised video of HIV sharing; If you've decided to share with a particular person – where, when and how to share, and what to say; practising sharing; after sharing.
- Session 4 – Goal Setting and Planning: Developing a personal sharing plan: assessing goals including reasons for goal and relationship between goal and personal values; developing an action and coping plan. Participants were encouraged to keep a copy of their plan to refer to in the future (Evangeli, Gnan et al., 2024).

During the intervention sessions, videos and group discussions were integrated with interactive exercises. A workbook was provided to all participants in the intervention group.

Data collection

Demographic information for HEADS-UP study participants was self-reported using a questionnaire at baseline with viral load measurements collected from clinical records. Semi-structured interview guides for participants and therapists were drafted and developed by the research team, in consultation with project advisory groups. The English interview guides were translated into Luganda by a first-language Luganda speaker. Topics that were covered in the participant interviews included relationships with other participants and therapists, perceived knowledge, appropriateness and satisfaction with the intervention, experiences of being in the SOC condition and HIV-sharing experiences during the follow-up period. Example participant questions include, "*What effect did the sessions have on you?*", "*Is there anything else you would have wanted to cover in the intervention that you didn't get a chance to?*", and "*What did you enjoy the most?*".

The therapists' interview guides covered the following areas: relationships with participants and therapists; group cohesiveness; the perceived impact of the intervention; acceptability, appropriateness and satisfaction with the intervention; and experiences of training, supervision and delivering the intervention. Example therapist questions included, "*How did you find the intervention training?*" and "*Were there any situations which were difficult for you to deal with during the intervention?*"

Face-to-face interviews were conducted in Uganda, and both face-to-face and remote video interviews were conducted in the UK, between March 2021 and April 2022. Interviews were conducted post-intervention (immediately after the final intervention session) for intervention condition participants and at the 6-month follow-up (6 months from baseline) for participants from both conditions. The UK Interviews were conducted in English. The Uganda interviews were conducted in English and Luganda, according to participant preference, and all interviews were recorded.

Interviews were carried out by HEADS-UP UK and Uganda study coordinators. The UK study coordinator was a female, doctoral-level researcher with considerable experience in conducting qualitative interviews. The Uganda study coordinator was a female researcher with more limited qualitative interview experience. Both interviewers had met the participants as part of the HEADS-UP recruitment process. They were both trained and supervised by the final author, an experienced qualitative researcher at the professorial level. Interviews conducted in Luganda were translated into English. All interviews were transcribed. Participants (aside from therapists) were reimbursed for their involvement and for travel expenses incurred.

Data analysis

Qualitative data were analysed using line-by-line coding by two master's level students, who were not the interviewers in this study. Thematic analysis was conducted (Braun & Clarke, 2006). Responses were read and reread to increase familiarity with the data and initial codes were developed for every sentence. When the English translation of phrases was ambiguous for the Uganda transcripts, this was checked with a first-language Luganda speaker. Codes were written and scanned for patterns which are reported as themes and subthemes. All coding and consolidating of themes were carried out by the final authors.

Ethics

The study was approved by ethics committees from the UK NHS, collaborating institutions and the Uganda National Council for Science and Technology. Written, informed consent was sought from all participants.

Quality

Quality was maintained by adhering to published standards (Elliott et al., 1999). Participant demographic data served to situate the sample. Participant demographic data served to situate the sample. Frequent discussions between authors helped to maintain reflexivity. Credibility checks of the first authors' coding were used (by the final author). Finally, the analysis was grounded in examples.

Results

A total of 24 interviews were analysed. There were ten Uganda young people participants (6 interventions, 4 SOC conditions) and nine UK young people participants (6 interventions, 3 SOC conditions) (Table 1). In addition, there were five therapists (3 Uganda – 1 psychosocial counsellor, 1 social worker, 1 peer worker; 2 UK – 1 clinical nurse specialist, 1 peer worker) interviewed. Table 2 shows seven focussed and 15 theoretical codes. These covered many experiences shared by participants in both countries, with a minority being more evident in one country. A small number of codes related specifically to the therapists' experiences of the intervention.

Benefits of peer support

Connecting participants with other young adults living with HIV

Most participants in both countries spoke about the benefits of peer support from other study participants. Many enjoyed listening to others sharing their thoughts and experiences about living with HIV and HIV sharing. This was a safe space where they could reflect on the fact that others were experiencing similar issues to them. Some participants also gained a sense of normality or confidence from their fellow participants:

> The intervention made me to 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 and how the community take us when we disclose. It relieved me from a burden of thinking that I was passing through a situation alone. [Uganda Intervention 1]

Table 1. Young person participant characteristics.

			Uganda participants			
Condition	Number	Age at interview date (years)	Gender	Country of Birth	Time point of interview*	VL at baseline (copies)
Intervention	1	20	Male	Uganda	Post intervention	<200
Intervention	2	22	Male	Uganda	6 months	<200
Intervention	3	22	Female	Uganda	Post intervention	≥200
Intervention	4	25	Female	Uganda	Post intervention	<200
Intervention	5	24	Female	Uganda	6 months	<200
Intervention	6	24	Female	Uganda	6 months	<200
Standard of Care	1	23	Female	Uganda	6 months	≥200
Standard of Care	2	25	Female	Uganda	6 months	<200
Standard of Care	3	22	Male	Uganda	6 months	<200
Standard of Care	4	22	Male	Uganda	6 months	≥200
UK participants						
Condition	**Number**	**Age (years)**	**Gender**	**Region of Birth**	**Time point of interview**	**VL at baseline (copies)**
Intervention	1	21	Female	Southern Africa	6 months	Unknown
Intervention	2	19	Female	Europe	Post intervention	<200
Intervention	3	29	Male	Europe	Post intervention	Unknown
Intervention	4	24	Female	Europe	Post intervention	<200
Intervention	5	23	Female	Southern Africa	6 months	<200
Intervention	6	23	Female	Southern Africa	6 months	<200
Standard of Care	1	24	Male	East Africa	6 months	<200
Standard of Care	2	26	Female	Southern Africa	6 months	<200
Standard of Care	3	28	Female	Southern Africa	6 months	<200

Table 2. Table of themes.

Theoretical codes	Focused codes
Benefits of Peer Support.	Connecting participants with other HIV-positive young adults. Young adults learn from the experiences of each other.
Educational Impact.	Learning new skills. Gaining knowledge and understanding about HIV. Furthering career and working in research (Therapist only).
Feelings Towards HIV Status Sharing.	The difficulty people face when sharing. Discussing sharing in and out of the clinic.
Feelings towards the study process.	What worked well. What did not work.
Application of Skills and Knowledge After the Intervention.	Using the intervention skills outside the study. Participants experience of HIV sharing.
Working with Other Study Therapists (Therapists Only).	Working with the other therapist during the sessions (Therapist only). Working with the other therapist outside the sessions (Therapist only).
Experience of the Study Training (Therapists Only).	Valuable experiences and confidence building. Difficulties with the training programme.

> I used to see myself in another way but when I participated in the study, I saw different young people … so … it made me to realize that I wasn't different … Now I feel normal as any other person. [Uganda Intervention 5]

> I was … inspired by other peoples' stories … it made me more comfortable in some way about my HIV … seeing how other people are just confidently live with it and they confidently share with other people … I think it just … boosted my confidence a little … and just, sort of, like owning it. [UK Intervention 5]

Participants in both countries gained a sense of belonging. The intervention offered an opportunity to bond with peers and develop new friendships. Several participants in both countries had a positive change of attitude towards their HIV status. Some said they no longer wished to live in isolation and began networking with other young adults with HIV:

> I can say that I … feel good because these interventions have changed my life. They have taught me how to live without isolating myself and how to live a peaceful, good, positive life … … We formed a WhatsApp group and many of us we are on that platform. So, we communicate … on a personal basis. Some become my friends. [Uganda Intervention 1]

> We have a group [social media app], so probably a month ago that we were all active in the group chat. It was just like a friendly chat. [UK Intervention 6]

In both the UK and Uganda, participants spoke about the benefits of connecting with other young adults, particularly when this need was not being currently met:

> I have never got even a single chance to talk about HIV sharing in the usual clinic … every person at the clinic minds his or her own business. [Uganda Intervention 5]

> I also feel like as an adult everybody tends to stop giving you as much support when you reach adulthood. When it's, like, you're 16 or you're 18, now so "do it by yourself you don't need anybody to hold your hand" … it should be included in that bracket because I don't want someone to just feel on their own with it. Especially when all these, like. mental health is, like, a big problem. [UK Intervention 4]

Young people learning from the experiences of each other

Several participants in both countries spoke about learning from the experiences of their peers. Different perspectives from peers helped participants reflect on their own sharing journey and how to cope with sharing in the future:

> Listening and hearing all these other stories, it … opened my eyes … and I was able to ask more questions and just find out more for my own sake about if I do have to share again. [UK Intervention 6]

> What I enjoyed most … was the interaction. Like, people exchanging the ideas, listening from different people, and hearing from their point of view how they see things. [Uganda Intervention 3]

Study therapists also observed the positive effects of learning from peers:

> I think they really gained a lot of knowledge and confidence … what also really helped is that there were loads of different experiences within the group. [UK Therapist 2]

Educational impact

Learning new skills

Several participants mentioned different skills they learned during the intervention and how this helped them on their HIV-sharing journey. Participants felt better able to communicate their status. They became confident with planning how to share their status and reflecting on their feelings and thoughts about sharing:

> I learned quite a lot … the thought process when it comes to sharing … who are you going to share with, where you going to do it, what are you going to say … something I actually never thought about. [UK Intervention 5]

> [I learned] When to disclose, how to disclose, where have you disclosed from? Whom have you disclosed to, and how ready are you. [Uganda Intervention 5]

Gaining knowledge and understanding about HIV

Participants in both countries mentioned that the sessions were very educational. They gained a lot of new information about HIV. This helped them develop a more positive outlook about HIV, with an increased motivation to share:

> What I liked most was the U=U campaign because I was green about it and I usually asked myself many questions about it, but I learnt it from the intervention. [Uganda Intervention 5]

> I feel like I've learned a lot … . I learnt that apparently now mothers with HIV … can breastfeed their babies and I didn't know that … so to hear that … we've come a long way in a couple of years. [UK Intervention 2]

Participants in the UK intervention arm spoke about feelings of empowerment:

> I would say it empowered me to move my timeline forward … it was more like "you can do this, you actually have it in you, stop messing around, like there's no time like the present" … … The study can really actually start to tackle the social stigma that everybody seems to want to talk about but we're no closer, and I think this is like a step in the right direction … . I think for me … is about refocusing and reclaiming and being empowered. That you have the ability to make sound decisions. [UK Intervention 3]

Furthering career and working in research (Therapists only)

Therapists felt they could offer more support to young people living with HIV after the intervention. The new skills acquired during the intervention complimented therapists' usual practice. Therapists felt better able to run group-based sessions or engage with different kinds of research after the intervention:

> [I applied for the role] to learn a little bit more about research but particularly qualitative research and develop skills, communication skills, those sorts of things and focus on an area which I already find incredibly important … and understand how difficult it is for people. [UK Therapist 1]

> It was so great … . I learnt many things that I didn't know about making and running groups. [Uganda Therapist 2]

Feelings towards HIV status sharing

Difficulty people face when sharing

Many participants spoke about the difficulties they face when sharing. Before the intervention, many said they would never share. After the intervention, participants mentioned that the study gave them the courage to share their status with more people, gave them more self-confidence and helpful strategies for sharing:

> It had a really positive effect, and I even got the courage to perform at the conference. That was something that I was really dreading and scared about. But … taking part in these studies and interventions helped me become more confident. [UK Intervention 1]

> What did I enjoy the most? … the sharing plan … because it was like personalised … to me and my situation and what I would want to do. [UK Intervention 5]

Discussions of sharing in and out of the clinic

Most participants discussed the extent to which sharing rarely comes up in their usual clinic appointments. Even when young people did seek advice, clinicians seemed unable to offer enough support in most circumstances:

> Um, it's [sharing] not really ever discussed [at clinic] to be honest. It's not a topic that's that comes up unless … I just want to let them know that 'oh I've told so and so' … that's it. [UK Intervention 6]

> I have never got a chance of finding such a discussion [about sharing] in the clinic when I come to get my drug refill. [Uganda Intervention 6]

> It comes up a lot in clinic and it often feels like there's very little that you can really say or offer, often people are asking for ideas about how they could do something. [UK Therapist 1]

In contrast to the intervention arm, no participants in the standard of care condition mentioned sharing their status after completing the study. Some participants also expressed their unwillingness to ever share soon:

> I haven't told anybody … I haven't disclosed to anybody new should I say. [UK SoC 2]

> I don't normally discuss my personal life with people apart from my family. [Uganda SoC 4]

Feelings towards the study process

What worked well

The feedback from participants in both countries was very positive. The participants mentioned getting on very well with the study therapists. This created a comfortable space for participants to express their thoughts, feelings and experiences about sharing:

> 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. [Uganda Intervention 1]

> We were united … every person had to give something meaningful. [Uganda Intervention 6]

> I just suck at prioritising things so it's great to be reminded … so even if I do double book I was like, yes, this is happening on, put in my calendar, that's it. [UK Intervention 3]

Participants liked the balance between the structure and flexibility of the sessions. They benefitted from discussing topics and feelings most important to them at the time. The variety of exercises delivered in the intervention was appealing and enhanced the participants' experience. In many cases, participants said how a favourite session had helped them in their sharing journey:

> We made a lot of discussions; questions were many and even we were taught about different ways of disclosing. But what I enjoyed most was the acting part of the session [session 3 roleplay] … you could imagine yourself doing it. [Uganda Intervention 5]

> I enjoyed session four [personalised sharing plan] … I think the questioning made me realise there were somethings I hadn't really ironed out … session four was probably one of my favourites but the journey to get there … the way the sessions were designed … that we needed to go through one, two and three to reach four … I had a better appreciation of it because it, sessions one, two and three help me step outside of myself. [UK Intervention 3]

What did not work

Participants in the UK reflected on the absence of external support at the end of the intervention, despite information offered about community organisations. Many said that this would be useful going forward:

> I think just an ongoing group would be something that I would like … it's just a free space where you feel like you can talk about anything and doesn't even have to be HIV related … just brings a bit of comfort, um … where you just feel free, and you can talk about anything. [UK Intervention 5]

> I feel like it would be – I thought it would be good if there was like ongoing support groups for people that felt like they wanted to talk about anything like in relation to, for example, the session or just general HIV in general, sharing in general so yeah, I feel like it would be good at those, I mean a support group. [UK Intervention 2]

Application of skills and knowledge after the intervention

Using the intervention skills outside the study

Participants in both countries discussed how they had (or intended to) use the skills and knowledge acquired from the intervention. Many felt they could now approach sharing their status more confidently with important people in their lives (friends, siblings and partners):

> Um well obviously we made that plan on the last one (session) and that's something that I'm going to follow through on next weekend actually … that was helpful because I don't feel like I would have done it … if we hadn't had that talk. [UK Intervention 4]

> The U=U … I told her everything … she even cried … but then at the end of it all she told me that the good thing you have told me earlier … as a person I got peace of mind. [Uganda Intervention 2]

All therapists used the skills and knowledge acquired from the intervention. Study therapists who also worked as clinicians used the HEADS-UP material in clinical settings, enhancing the support they offered at the clinic.

> I'll bring it up every time with them. I'll ask them to think about if there's anyone they had ever thought about they would want to tell, and that … these are conversations that we can have … in clinic if that's something they want. [UK Therapist 1]

> Currently I still refer to this information because on a daily basis. I meet people born and not born with HIV, but they have disclosure issues and I have been able to help them. [Uganda Therapist 3]

Working with other study therapists

Working with the therapist during the sessions (Therapist only)

All study therapists spoke highly of their colleagues, valuing each other's strengths and approaches. They often looked to each other as a source of support during the sessions.

> I think I was kind of more like motivational; 'oh it's ok we can do this. It's fine, it will be alright, don't worry about it … . she supported me as well when I had like really difficult nights and stuff and really difficult situations [UK Therapist 2]

> Where there was a mistake … or going astray, another could come in. So, there was that way of coordinating. We thought that the bond was built [Uganda Therapist 1]

Working with the therapists outside the sessions (Therapists only)

Study therapists found it useful to prepare for the session beforehand. This was used as an opportunity to establish a good working relationship and motivate one another.

> Briefing with XX (other study therapist) was actually really nice as well because we were able to … like, speak … that was really good. Just having someone

> where you know that you can also like bounce off of, yeah [UK therapist 2]

Therapists would debrief after each session. This was a time to reflect on their own performance or discuss challenges they faced and how to overcome them next time. Having a peer to confide in seemed particularly important to therapists.

> You know XX (other therapist) and I would talk about it, and sort debrief afterwards and talk things through um … and just yes, just think about things a little bit together and I think that was really nice being able to do that. She was great at kind of checking in with me as well at the beginning and stuff you know, there was a nice kind of mutual support. [UK Therapist 1]

> Particularly when it comes to XX (other study therapist) we could have some ample time (umm) to discuss the way forward, we could have some time to discuss about the session we had just completed (umm) and even XX (other study therapist), well, we could get some time and we discuss so that we can avoid mistakes for the next sessions ahead of us. [Uganda Therapist 2]

Experience in study training

Valuable experiences and confidence-building

The UK therapists liked the breadth of training they received before running the intervention. They acquired skills in basic counselling, active listening and asking open questions, as well as practical skills for running groups. The intervention manual was also a good resource for therapists to revisit the training when needed.

> Sometimes we did roleplays, which was good … because I like learning as I go so. Especially when it came to, like, building empathy or like having skills. That was great because we were able to actually put it into real life [UK Therapist 2]

> I would say that the manual was very extensive … and very helpful. [UK Therapist 1]

All the Uganda therapists spoke highly of the study training but did not discuss the breadth of the training. In contrast to the UK therapists (discussed in the next section), the Uganda therapists said they felt prepared to deliver the intervention and felt supported by the training.

> By the time we meet these clients we were … ready and well equipped. [Uganda Therapist 1]

> After the training I felt that am almost 90 percent that I can deliver what I have been trained. [Uganda Therapist 2]

> We were lucky with the team that I was working with because they had to first train us on what we were supposed to do … background information, what the study is about, what to expect and how we are supposed to go about it. [Uganda Therapist 3]

Difficulties with the training

A key difficulty touched on by the UK therapists was the amount of new information to learn during the training.

> Um, to be honest I found it quite intense sometimes. Because it was a lot of like information to retain. Um, and I think as well because it was like one – it was like one day in the week, it was yes it was just thought it was so much to retain in that space, in that time. [UK Therapist 2]

> I had made notes, there is a very extensive manual … I just had to go back over things myself and spend quite a lot of time doing that … because … I need that to be able to you know … to feel ready [UK Therapist 1]

> Yes, so … not very prepared but, I don't know I think … that is not quite true as well if I was to say, 'not very prepared' that might – that might have been about how confident do I feel about that I was ready to. [UK Therapist 1]

> Yes, to be honest I felt like pretty prepared … I guess the restart [referring to a gap between the main block of training and the final element of training] was a little bit – not necessarily rushed but it really did feel like 'oh right okay, were back to it' … so yeah it did kind of like leave us a little bit unsure. [UK Therapist 2]

The UK therapists experienced some difficulty in completing the study training online rather than in person. Cultural differences may have also made the intervention material more challenging to engage with as the training was conducted with therapists from both countries.

> I understand that it [The training] had to be with … the Ugandan people as well. I think that was a little bit difficult. I think that there are … different sort of … cultural issues if you like … That made it a little bit more complicated. [UK Therapist 1]

Discussion

This study investigated the experiences of a novel HIV-sharing intervention among therapists and young adults living with PAH in Uganda and the UK. The qualitative findings suggest that the intervention was experienced positively in both countries, despite cultural differences. Participants who received the intervention expressed feelings of empowerment, a more positive attitude towards their HIV status, increased HIV knowledge, and greater motivation to and confidence in sharing their status after completing the intervention. Five key themes were identified from the qualitative interviews with the participants and the therapists: the benefits of peer support, educational impact, the study process, feelings towards HIV status and the application of skills and knowledge after the intervention. Two additional themes were specific to therapists: working with other study therapists and the experience of the study training.

The perceived benefit of peer support from other HEADS-UP study participants was a central finding. Participants enjoyed discussing ideas and sharing experiences in a safe space with other young people living with PAH. Many participants mentioned how this reduced their feelings of loneliness and was an opportunity for them to learn from other participant's experiences. This finding was consistent with studies across a range of populations of people living with HIV (Lut et al., 2017; Magidson et al., 2019; Wogrin et al., 2021).

Participants in the intervention group described the sessions as highly educational, both in relation to HIV sharing skills and regarding general information about HIV. This included learning about U=U (Rodger et al., 2019) in both countries. Gains in knowledge about HIV sharing related to strategies to plan how to share, and how to handle both positive and negative responses when sharing with others. Disclosure interventions using educational techniques have been shown to increase HIV sharing in other populations of people living with HIV (Schulte et al., 2021). In the current study, learning HIV sharing skills (e.g. planning how to share) appeared to increase confidence in being able to share, consistent with the intervention's conceptual model. This finding is in line with a trend towards increased HIV pro-disclosure cognitions and affect, and HIV disclosure intention seen in the quantitative evaluation of HEADS-UP (Evangeli, Gnan et al., 2024).

This study found that HIV sharing was rarely discussed in routine clinical care, indicating that the intervention was not mirroring conversations with professionals that were already occurring. In addition, one therapist in this study noted that they had little to offer when the issue arose prior to being trained on the HEADS-UP intervention. This may be a consequence of the absence of training and guidance for professionals on how to support people living with HIV around HIV status sharing. Guidelines for how to offer HIV-sharing support should be developed.

One consistent finding was that participants felt that they needed more ongoing psychosocial support, for example, through support groups. Many participants mentioned how speaking with others living with PAH would reduce social isolation and mental health problems. It is notable that the quantitative HEADS-UP findings showed higher levels of wellbeing in intervention participants than in those allocated to the standard of care condition, despite the intervention not being designed to be primarily focused on wellbeing (Evangeli, Gnan et al., 2024). This finding may be due to the intervention fulfilling generic support needs, rather than needs specific to HIV sharing. In addition, the qualitative findings suggested that the intervention, for some, resulted in a more positive attitude towards their HIV status. The latter was one of the aims of the intervention (i.e. reducing internalised HIV stigma) and is consistent with the intervention's conceptual model (Evangeli, Gnan et al., 2024).

Many participants said that they felt like they could never share their status before taking part in the intervention. The subjective difficulty in HIV sharing in this population has been reported in many previous studies (Gabbidon et al., 2020; Hogwood et al., 2013; Zgambo et al., 2021) and is consistent with the low levels of HIV sharing reported in the quantitative HEADS-UP analysis (Evangeli, Gnan et al., 2024). The findings are also consistent with evidence that young people living with HIV would like more support and guidance around HIV sharing (Bott & Obermeyer, 2013).

Regarding the strengths of the study, we aimed to sample representatively, and the response rate was good. Steps were taken to ensure rigour in the analysis. The sample size was sufficient to suggest that the data saturation may have been met for most of the themes. The longitudinal nature of the data collection was an additional strength. Limitations include the possibility of recall bias, the absence of member checking, and the fact that it is not known how transferable the findings are to other populations of young people living with perinatally acquired HIV. In addition, the fact that the analysis was carried out by two English-speaking researchers based in the UK may have meant that some of the nuance inherent in the Uganda data may have been missed.

The main practice implication from this study is that more support should be provided to help young adults living with PAH. This relates to both HIV sharing-specific support (as this did not seem to occur in standard care) and more generic psychosocial and mental health support. Many participants mentioned how the support offered reduces once they enter adult care. It is essential to continue providing support services from adolescence into young adulthood for individuals living with PAH. Peer support should be part of this provision, given the clearly beneficial effects seen in the current study and in other studies (Aurpibul et al., 2023). Reducing isolation and preventing mental health difficulties are vitally important goals, given that they are correlated with a range of negative outcomes, for example, lower levels of ART adherence (Evangeli, 2018).

There are also implications of this study for the evaluation of HEADS-UP and other HIV-sharing interventions. This study corroborated the findings that the HEADS-UP intervention was feasible and acceptable (Evangeli, Gnan et al., 2024). If HEADS-UP proceeds to a full-powered RCT, then the qualitative findings suggest that additional support should be offered to participants, for example, follow-up support after difficult sessions and support groups for participants following the intervention. This study also suggests that future research could develop and test the intervention with younger people with PAH, perhaps soon after HIV naming. In addition, many issues associated with sharing an HIV status are similar regardless of the population. Adapting the HEADS-UP intervention for other populations of people living with HIV could, therefore, be undertaken.

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Authors' contributions

AO'K: formal analysis, writing and reviewing; JP: formal analysis, writing and reviewing. ME: funding acquisition, study design, conceptualisation, methodology, project administration, supervision, writing, reviewing and editing. JS: study design and supervision. SF, GF, CF and VM: study design. GG and AU: project administration and investigation. All authors were involved in reviewing. All authors read and approved the final manuscript.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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Ethics approval

The study was given ethical approval by a UK NHS Research Ethics Committee (IRAS:252582) and the UK Health Research Authority, by the Uganda National Council of Science and Technology (HS2636), and by institutional review boards at the Joint Clinical Research Centre, Kampala, Uganda (JC0319) and Royal Holloway, University of London, UK.

Data availability statement

Anonymised electronic data from the study are available on the Figshare data repository, freely accessible under the Creative Commons CC BY licence.

References

Aurpibul, L., Tangmunkongvorakul, A., Detsakunathiwatchara, C., Masurin, S., Srita, A., Meeart, P., & Chueakong, W. (2023). Social effects of HIV disclosure, an ongoing challenge in young adults living with perinatal HIV: A qualitative study. *Frontiers in Public Health*, *11*, 1150419. https://doi.org/10.3389/fpubh.2023.1150419

Bondarchuk, C., Lemon, T., Earnshaw, V., Rousseau, E., Sindelo, S., Bekker, L. G., Butler, L., & Katz, I. (2025). Disclosure events and psychosocial well-being among young South African adults living with HIV. *International Journal of Behavioral Medicine*, *32*, 124–134. https://doi.org/10.1007/s12529-024-10291-5

Bott, S., & Obermeyer, C. M. (2013). The social and gender context of HIV disclosure in sub Saharan Africa: A review of policies and practices. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, *10*(Suppl. 1), S5–S16. https://doi.org/10.1080/02664763.2012.755319

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.

CHARS. (2024). *Annual report 2022–23*. https://www.ucl.ac.uk/chars/sites/chars/files/chars_report_jan_2024_updated.pdf

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, *38*(3), 215–229. https://doi.org/10.1348/014466599162782

Evangeli, M. (2018). Mental health and substance use in HIV-infected adolescents. *Current Opinion in HIV and Aids*, *13*, 204–211. https://doi.org/10.1097/COH.0000000000000451

Evangeli, M., & Foster, C. (2014). Who, then what? The need for interventions to help young people with perinatally acquired HIV disclose their HIV status to others. *AIDS*, *28*(Suppl. 3), S343–S346. https://doi.org/10.1097/QAD.0000000000000334

Evangeli, M., Foster, C., Musiime, V., Fidler, S., Seeley, J., & Gnan, G. (2020). A randomised feasibility trial of an intervention to support sharing of HIV status for 18–25-year olds living with perinatally acquired HIV compared with standard care: HIV Empowering Adults' Decisions to Share-UK/Uganda Project (HEADS-UP). *Pilot and Feasibility Studies*, *6*(1), 141. https://doi.org/10.1186/s40814-020-00688-w

Evangeli, M., Gnan, G., Musiime, V., Fidler, S., Seeley, J., Frize, G., Uwizera, A., Lisi, M., & Foster, C. (2024). The HIV Empowering Adults' Decisions to Share: UK/Uganda (HEADS-UP) study—A randomised feasibility trial of an HIV disclosure intervention for young adults with perinatally acquired HIV. *AIDS and Behavior*, *28*(6), 1947–1964. https://doi.org/10.1007/s10461-024-04294-2

Gabbidon, K., Chenneville, T., Peless, T., & Sheared-Evans, S. (2020). Self-disclosure of HIV status among youth living with HIV: A global systematic review. *AIDS and Behavior*, *24*(1), 114–141. https://doi.org/10.1007/s10461-019-02478-9

Henderson, M., Fidler, S., & Foster, C. (2024). Adults with perinatally acquired HIV; Emerging clinical outcomes and data gaps. *Tropical Medicine and Infectious Disease*, *9*(4), 74. https://doi.org/10.3390/tropicalmed9040074

Hogwood, J., Campbell, T., & Butler, S. (2013). I wish I could tell you but I can't: Adolescents with perinatally acquired HIV and their dilemmas around self-disclosure. *Clinical Child Psychology and Psychiatry*, *18*(1), 44–60. https://doi.org/10.1177/1359104511433195

Jopling, R., Mutsvuke, W., Fertig, M., O'Cleirigh, C., Mangezi, W., & Abas, M. (2024). What if I got rejected by the girl? I would rather stop the pills": Barriers and facilitators of adherence to antiretroviral therapy for emerging adults aged 18-29 living with HIV in Zimbabwe. *AIDS Care*, *36*(Suppl. 1), 168–178. https://doi.org/10.1080/09540121.2024.2332462

Lut, I., Evangeli, M., & Ely, A. (2017). "When I went to camp, it made me free": A longitudinal qualitative study of a residential intervention for adolescents living with HIV in the UK. *Children and Youth Services Review*, *79*, 426–431. doi:10.1016/j.childyouth.2017.07.002

Mabasa, R. A., Madiba, S., & Mothiba, T. M. (2023). Structural, familial, and psychosocial factors affecting long-term antiretroviral treatment adherence amongst adolescents living with perinatally acquired HIV in Limpopo, South Africa. *International Journal of Environmental Research and Public Health*, *20*(22), 7074. https://doi.org/10.3390/ijerph20227074

Magidson, J. F., Joska, J. A., Regenauer, K. S., Satinsky, E., Andersen, L. S., Seitz-Brown, C. J., Borba, C. P.C., Safren, S. A., & Myers, B. (2019). "Someone who is in this thing that I am suffering from": The role of peers and other facilitators for task sharing substance use treatment in South African HIV care. *International Journal of Drug Policy*, *70*, 61–69. https://doi.org/10.1016/j.drugpo.2018.11.004

Mellins, C. A., & Malee, K. M. (2013). Understanding the mental health of youth living with perinatal HIV infection: Lessons learned and current challenges. *Journal of the International AIDS Society*, *16*(1), 18593. https://doi.org/10.7448/IAS.16.1.18593

Mugo, C., Seeh, D., Guthrie, B., Moreno, M., Kumar, M., John-Stewart, G., Inwani, I., & Ronen, K. (2021). Association of experienced and internalized stigma with self-disclosure of HIV status by youth living with HIV. *AIDS and Behavior*, *25*(7), 2084–2093. https://doi.org/10.1007/s10461-020-03137-0

Nostlinger, C., Bakeera-Kitaka, S., Buyze, J., Loos, J., & Buve, A. (2015). Factors influencing social self-disclosure among adolescents living with HIV in Eastern Africa. *AIDS Care*, *27*(Suppl. 1), 36–46. https://doi.org/10.1080/09540121.2015.1051501

Rochat, T. J., Stein, A., Cortina-Borja, M., Tanser, F., & Bland, R. M. (2017). The Amagugu intervention for disclosure of maternal HIV to uninfected primary school-aged children in South Africa: A randomised controlled trial. *The Lancet HIV*, *4*(12), e566–e576. https://doi.org/10.1016/S2352-3018(17)30133-9

Rodger, A. J., Cambiano, V., Bruun, T., Vernazza, P., Collins, S., Degen, O., Corbelli, G. M., Estrada, V., Geretti, A. M., Beloukas, A., Raben, D., Coll, P., Antinori, A., Nwokolo, N., Rieger, A., Prins, J. M., Blaxhult, A., Weber, R., Van Eeden, A., … Janeiro, N. (2019). Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV-positive partner taking suppressive antiretroviral therapy (PARTNER): final results of a multicentre, prospective, observational study. *The Lancet*, *393*(10189), 2428–2438. https://doi.org/10.1016/S0140-6736(19)30418-0

Schulte, M. T., Armistead, L., Murphy, D. A., & Marelich, W. (2021). Multisite longitudinal efficacy trial of a disclosure intervention (TRACK) for HIV+ mothers. *Journal of Consulting and Clinical Psychology*, *89*(2), 81–95. https://doi.org/10.1037/ccp0000622

Serovich, J. M., Laschober, T. C., Brown, M. J., Kimberly, J. A., & Lescano, C. M. (2020). Effects of a decision-making intervention to help decide whether to disclose HIV-positive status to family members on well-being and sexual behavior. *Archives of Sexual Behavior*, *49*(6), 2091–2101. https://doi.org/10.1007/s10508-020-01703-0

Thoth, C. A., Tucker, C., Leahy, M., & Stewart, S. M. (2014). Self-disclosure of serostatus by youth who are HIV-positive: A review. *Journal of Behavioral Medicine*, *37*(2), 276–288. https://doi.org/10.1007/s10865-012-9485-2

Uganda AIDS Commission. (2022). *Uganda HIV & AIDS factsheet.*

UNAIDS. (2021). *Young people and HIV*. https://www.unaids.org/sites/default/files/media_asset/young-people-and-hiv_en.pdf

Weintraub, A., Mellins, C. A., Warne, P., Dolezal, C., Elkington, K., Bucek, A., Leu, C.-S., Bamji, M., Wiznia, A., Abrams, E. J. (2017). Patterns and correlates of serostatus disclosure to sexual partners by perinatally-infected adolescents and young adults. *AIDS and*

Behavior, *21*(1), 129–140. https://doi.org/10.1007/s10461-016-1337-6

WHO. (2018). *WHO recommendations on adolescent sexual and reprodcutive health and rights*.

Wogrin, C., Willis, N., Mutsinze, A., Chinoda, S., Verhey, R., Chibanda, D., & Bernays, S. (2021). It helps to talk: A guiding framework (TRUST) for peer support in delivering mental health care for adolescents living with HIV. *PLoS ONE*, *16*(3), e0248018. https://doi.org/10.1371/journal.pone.0248018

Zgambo, M., Arabiat, D., & Ireson, D. (2021). It cannot happen, never: A qualitative study exploring youth views on disclosure of HIV diagnosis to their sexual partners in Southern Malawi. *Journal of the Association of Nurses in AIDS Care*, *32*(6), 652–661. https://doi.org/10.1097/JNC.0000000000000238