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RESEARCH ARTICLE

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The process of developing an HIV disclosure intervention for youth with perinatally acquired HIV: The HIV Empowering Adults' Decisions to Share – UK/Uganda Project (Heads-Up)

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ABSTRACT

Sharing one's HIV status with others (onward HIV disclosure) for youth with perinatally acquired HIV (PAH) is often difficult but may assist with challenges associated with living with HIV. We describe the development of an intervention to help HIV-sharing decision-making for UK and Ugandan youth with PAH. The methods included : (1) semi-structured interviews with 50 participants (20 with PAH patients aged 18–25 years, 20 friends, family or partners and 10 professionals), (2) a survey of 57 UK participants with PAH patients aged ≥17, (3) the development of an intervention conceptual model, (4) intervention development, including obtaining intervention feedback from 13 youth with PAH. The survey showed that group (23/57; 40%) and mixed individual and group formats (21/57; 37%), mixed gender groups (52/57; 91%) and peer worker involvement (54/57; 95%) were preferred. The interviews highlighted the importance of overcoming feelings of shame and accepting one's status before sharing, having support to feel confident to share, personal values playing a part in sharing decisions and friends and partners explaining that they had not been educated about HIV until someone had shared their status with them. We describe the finalised intervention, and strengths and limitations of the intervention development process are outlined.

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HIV; disclosure; feasibility; intervention; good health and well-being

Introduction

The World Health Organisation (WHO) defines 'adolescents' as individuals in the 10–19 years age group, 'youth' as the 15–24 years age group and 'young people' as the age range 10–24 years (WHO, 2014). Globally, an estimated 3.1 million youth (aged 15–24 years) live with HIV (UNAIDS, 2023). An estimated 660,000 youth (aged 20–24) live with perinatally acquired HIV (PAH), with 88% in sub-Saharan Africa (Sohn & Davies, 2024). Although youth living with PAH share some similar challenges to those who have behaviourally acquired HIV (e.g. needing to adhere to lifelong antiretroviral therapy (ART), potentially compromised health, managing HIV stigma and the risk of onward HIV transmission), other stressors relate specifically to perinatal acquisition. Lifelong HIV infection acquired early in physiological and immunological development results in chronic clinical complications that can cause severe morbidity in early adult life (Henderson. et al., 2024). Youth living with PAH have often experienced multiple caretaking transitions and loss due to parental and/or sibling illness or death. Many have experienced suboptimal ART regimens in childhood, increasing their likelihood of developing drug resistance (Glenn et al., 2025; Patel et al., 2019).

ART can transform survival for *all* people living with HIV and prevent the risk of onward viral transmission to partners and infants. Daily adherence is, however, challenging and rates of viral suppression are variable

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globally in young people living with PAH (Rakhmanina et al., 2024). Unprotected sexual intercourse, in the context of globally variable ART coverage and low rates of viral suppression, presents a risk of onward (potentially drug resistant) HIV transmission to partners and offspring in all youth living with HIV. There may be specific ART adherence issues affecting youth with PAH. For example, experiences of parental loss may contribute to emotional distress and complicate treatment adherence (Enane et al., 2020). In addition, cognitive deficits that are prevalent in this population may affect ART adherence (Mwanza-Kabaghe et al., 2025). Some young people with PAH have subcortical white matter and frontostriatal abnormalities that affect emotion and behaviour regulation and place them at risk for mental health difficulties (Mellins & Malee, 2013). The evidence suggests higher rates of psychiatric disorders in young people with PAH than the general population, but similar rates than in young people exposed to but not living with PAH (2013; Too et al., 2021).

Sharing an HIV status with others (also known as self-disclosure or onward disclosure) has the potential to help all youth living with HIV manage challenges and both increase ART adherence and reduce onward HIV transmission. Where viral suppression has not been achieved, sharing an HIV status with partners may reduce onward HIV transmission, by fostering communication about safer sex strategies including the use of prevention methods such as condoms, pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP) and engagement in care/treatment if needed (Weintraub et al., 2017).

HIV status-sharing has also been shown to have a number of personal benefits for people living with HIV (Whembolua et al., 2016). Sharing may help to buffer HIV-related stress and improve wellbeing (Brown et al., 2019; Nostlinger et al., 2015). Being open about one's HIV status may facilitate obtaining social support from significant others, which in turn may assist constructive coping, enhancing self-esteem and other health-promoting behaviours (Nostlinger et al., 2015). Sharing one's HIV status may also enhance ART adherence, due to greater support from partners, friends or family and a reduced need to hide medication (Dessie et al., 2019; Mi et al., 2020). The fear of sharing HIV status is commonly cited as a barrier to ART adherence in young people living with PAH (Buchanan et al., 2012) and in other populations living with HIV, for example, women living in North America (Nawfal et al., 2024). There is also evidence of lower levels of HIV status-sharing being associated with poorer engagement with care in adults, young people and pregnant women (Izudi et al., 2021; Ojwang et al., 2016; Watson-Jones et al., 2012).

Globally, there are variable rates of self-reported sharing of an HIV status by youth living with HIV (Gabbidon et al., 2020). Rates of sharing to a partner range from 39% to 97% (Conserve et al., 2015). Rates appear to be particularly low in young people with PAH regardless of the context. A study in Kenya (Mugo et al., 2021) with a significant proportion of the sample living with PAH, reported that 66% of their sample of youth living with HIV who were either married or sexually active had not shared with their partners. Only 40% of youth living with PAH in the US reported sharing with all or most of their partners, and 45% reported sharing with no partners when having unprotected sex (Weintraub et al., 2017). In a study in Thailand, only 41% of sexually active 15- to 24-year-olds with PAH has shared their status with their partner (Boon-Yasidhi et al., 2021). In an older sample (18–25 years) in Uganda, 62% had shared their status with partners (Becker et al., 2024). There have also been low rates of HIV-sharing with other (non-partner) members of one's social network in studies involving young people in Eswatini, Kenya and Uganda (Dlamini & Mtshali, 2023a; Nostlinger et al., 2015).

Sharing an HIV status carries a unique challenge for youth with PAH. In comparison with people living with behaviourally acquired HIV, the HIV status of the youth will be known by family members before they are told. Parental hesitancy about sharing, including directives to not share from parents and caregivers, may be internalised (Hogwood et al., 2013) with an atmosphere of secrecy and limits to open communication about HIV affecting youth at home, in their community and in the clinic (Bernays et al., 2016; Kajubi et al., 2016). There may be concerns about revealing their mother's and potentially other family members' HIV status (Hogwood and Campbell, 2013).

The subjective difficulty of sharing one's HIV status in youth with PAH, particularly in intimate relationships, has been frequently reported in qualitative studies, with a fear of rejection and stigmatisation, a lack of confidence about sharing (low HIV disclosure self-efficacy) and fear of secondary disclosure from the recipient to others, cited as barriers to sharing in studies across North America, South America, Europe and Africa (Fernet et al., 2011; Galano et al., 2017; Greenhalgh et al., 2013; Hogwood et al., 2013; McGray et al., 2023; Wiener & Battles, 2006; Zgambo et al., 2021). The fear of rejection as a barrier to HIV status-sharing that has been reported in both high-income and low-income contexts (Fernet et al., 2011; Greenhalgh et al.,

2016; Smith et al., 2023; Zgambo et al., 2021). There remain important risks around sharing one's HIV status in all populations of people living with HIV, including the threat of rejection, humiliation, stigma and violence (Hult et al., 2012; Weintraub et al., 2017).

There have been few quantitative studies examining correlates of HIV status-sharing in people with PAH, with a tendency to examine different correlates in each. In a US study with adolescents/young adults, increased disclosure was associated with older age; being female; earlier age of learning one's serostatus; increased STD knowledge, greater disclosure intentions and better parent–child communication (Weintraub et al., 2017). In a study with adolescents from Uganda and Kenya, having disclosed to peers was significantly related to being older, being a paternal orphan, contributing to family income, regular visits to the HIV clinic and greater social support through peers. Low self-efficacy to disclose was negatively associated with the outcome variable (Nostlinger et al., 2015). In a study with youth in Kenya, those who had self-disclosed were more likely to be older, to report internalised stigma, experienced stigma and elevated depressive symptoms (57% vs. 30%, PR 1.8, 1.0–3.1) (Mugo et al., 2021). Across these studies, older age has been consistently associated with HIV status-sharing regardless of context.

There is a lack of HIV status-sharing interventions or guidance to support young people with PAH or professionals working with this population (Conserve et al., 2015; Evangeli & Foster, 2014; Kennedy et al., 2015). Existing interventions with adolescents or youth living with HIV have only tended to devote a single session to HIV status-sharing, in the context of broader interventions (Rotheram-Borus et al., 2001; Snyder et al., 2014). There is limited evidence of the effects of these interventions on onward HIV disclosure. It is likely that given the complexity of HIV-sharing decisions and the low rates of HIV status-sharing, more intensive interventions are required, as have been developed with working-age adults living with HIV in the US (Serovich et al., 2020). The unique issues in relation to HIV status-sharing for those with perinatally acquired HIV, and the evidence of lower rates of sharing than those with behaviourally acquired HIV (Abramowitz et al., 2009), suggest that novel interventions are required rather than attempting to adapt existing multi-session interventions for other people living with HIV.

The World Health Organisation (WHO) has called for work in this area, specifying the need for interventions to help adolescent disclosure decision-making, support caregivers and train providers (WHO, 2018). There is evidence that young people with HIV across different regions (Dlamini & Mtshali, 2023b; Murphy et al., 2003; Rochat et al., 2013; Thoth et al., 2013) and health care workers (Bott & Obermeyer, 2013) would like more HIV status-sharing support.

We have reported a feasibility study on a novel behavioural HIV-sharing intervention for youth with PAH in the UK and Uganda, with promising results (Evangeli et al., 2024). The rationale for developing the intervention in both a high-income/low-prevalence and low-income/high-prevalence context was the evidence of low rates of onward disclosure in both contexts. In this article, we present an outline of the intervention, along with a conceptual model and the steps taken to develop it. The latter was informed by intensive stakeholder engagement in each country, which was important given the need to consider country-specific disclosure laws and to create intervention materials that were relevant for each context. We used a series of strategies to achieve these objectives, including surveys, individual interviews and eliciting feedback on draft intervention exercises.

Methods

Setting

The study took place in two countries:

1. UK. Participants were recruited from five inner city National Health Service (NHS) clinics providing services for youth living with PAH across three large cities, as well as from one UK-based national HIV charity. These sites were chosen to maximise the chance of recruiting from a small UK population of youth with PAH.
2. Uganda. Participants were recruited from clinics in a medical research institute in the capital city, providing HIV care to youth living with PAH for ≥18 years. A single site was chosen because it was possible to recruit from one centre.

Intervention development

The intervention development was informed by the Six Steps in Quality Intervention Development (6SQuiID) model (Wight et al., 2016) and was consistent with the Medical Research Council (MRC) framework for developing and evaluating complex interventions (Skivington et al., 2021). The following steps were undertaken:

1. *Assessing (a) barriers to and facilitators of HIV status-sharing, (b) preferred components of HIV status-sharing interventions, (c) facilitators of involvement in HIV status-sharing intervention studies*

   Two approaches were used:

a. Survey. We carried out a paper-and-pencil survey of youth with PAH aged 17 years and older at a UK clinic. The following questions were assessed:
   - HIV status-sharing difficulty (*'I find it difficult to tell other people that I'm HIV positive',* with response options on a 5-point Likert scale from strongly disagree to strongly agree*)*
   - Intervention interest (*'I would be interested in taking part in sessions/a course to help me tell other people'*, with response options on a 5-point Likert scale from strongly disagree to strongly agree).
   - Features of a future HIV status-sharing intervention (format, gender mix, number of sessions, frequency, timing and number of therapists). For example, we asked,
     i. *'If we put on a course, it should be run: In a group (e.g. 4–6 young HIV+ people and one staff member); Individually (one young HIV+ person and one staff member)'; In pairs (e.g. 2 young HIV+ people and one staff member); With a mix of group, pair and individual sessions.*
     ii. *'In total, the course is likely to be around 6 hours long. How long should each session be?'* Response options were as follows: *1.5 hours (4 sessions); 2 hours (3 sessions); 3 hours (2 sessions); and 6 hours (1 session)*
   - Barriers to participation in an HIV status-sharing intervention. We asked participants to select from a list of responses and also allowed them to provide their own response.

b. Individual semi-structured interviews in both countries. Individual interviews were selected rather than using focus groups as sensitive topics are more frequently discussed in individual interviews compared with focus groups (Kaplowitz, 2000). The participants were youth with PAH aged 18 to 29 years in the UK and aged 18 to 25 years in Uganda with knowledge of their own HIV status; friends, family and partners of youth with PAH aged 18 years or over and aware of the HIV status of the youth with PAH (social network), and professionals working with youth with PAH. The interview guides were generated by the research team in collaboration with project advisory groups (one in each country). The project advisory groups consisted of health professionals in HIV care, academics, young people living with HIV and representative of charities/NGOs serving young people living with HIV. Separate interview guides were designed for youth living with HIV, social network and professionals. The interview questions addressed perceived barriers to and facilitators of sharing, potential components of a future sharing intervention and what might help youth to engage in sharing intervention research. For youth, the questions included, *'What are the reasons why you sometimes do not share your HIV status with others?'* and *'What has helped you to make decisions about sharing your status?'* For their social network, questions included, *'What do you think are the main reasons young people born with HIV share their status with others?'*, *'What is helpful if someone is sharing their HIV status with you?'* and *'What would be most helpful for friends, families and partners of young adults born with HIV if they were thinking about sharing their status with someone?'* For professionals, questions included, *'What advice do you or other professionals give young people about sharing their HIV diagnosis with others?'* and *'What is helpful for young people if they decide to share their status?'* Care was taken to avoid leading and closed questions throughout. The interviews were conducted by the UK and Uganda study coordinators, who were trained using role play techniques, by the first author (a clinical psychologist with experience of working with adults of all ages living with both perinatally and behaviourally acquired HIV). All interviews were recorded with an audio recorder and transcribed. Participants (aside from the professional group) were reimbursed for their time.

Youth with PAH were identified by clinicians and representatives of support organisations, attempting to sample those with a range of levels of onward HIV disclosure, and with a range of demographic characteristics. Youths identified were informed about the study verbally by a named clinician or support organisation representative by phone or at their next clinic/support organisation appointment. If they were interested in the study, they were put in touch with the study coordinator, who went through the participant information sheet with them and obtained informed consent. Youths were asked whether they could identify any friends, family members or regular partners whom they thought might like to take part in the study. The youth were asked to discuss the project with them and to provide the study coordinator's details. If the family member, friend or partner was interested in taking part in the study, the study coordinator went through the participant information sheet with them and obtained informed consent. Professionals working with youth with PAH were identified by the research team, attempting to sample across a range of clinics and support organisations. Again, the study coordinator went over the information sheet with them if they were interested. Written informed consent from the professional was obtained by the study coordinator or a member of the clinical team.

Reflexive thematic analysis (Braun & Clarke, 2019) was used to generate themes and subthemes. An inductive approach was used. After transcription, initial codes were generated by one member of the research team. A second member of the research team listened to several interviews, read through all of the transcripts and reviewed codes. Discrepancies between authors were resolved through discussion, and further revisions were made until agreement was reached. Themes and subthemes were developed and reviewed from the initial codes. These themes were then defined and named. Reflexivity was maintained through reflexive journaling, and repeated discussion between authors. This allowed for data comparisons and were vital in linking each stage of coding to the final development of themes.

2. *Developing an intervention conceptual model relevant to the study contexts*

The MRC framework for developing and evaluating complex interventions states that, 'developing a programme theory is essential to identifying key uncertainties and working out how the intervention might be evaluated' (p6) (Skivington et al., 2021). The process of developing a conceptual model of the intervention was informed by the theory of change (ToC) approach (De Silva et al., 2014). The aim was to develop a model to guide the development of the intervention and its evaluation. To develop the model, attention was given to the content of the preceding interviews, models of HIV disclosure decision-making and HIV disclosure anxiety (Chaudoir et al., 2011; Evangeli & Kagee, 2016; Evangeli & Wroe, 2017; Greene, 2009), evidence of HIV status-sharing correlates, barriers and facilitators (Bakeera-Kitaka et al., 2008; Nostlinger et al., 2015; Weintraub et al., 2017) and existing HIV maternal disclosure interventions (Armistead et al., 2022). A visual representation of the conceptual model was developed, similar to a ToC map (De Silva et al., 2014).

3. *Developing the intervention, obtaining feedback on intervention components for feasibility, understanding and acceptability and revising the intervention*

Intervention exercises were chosen to achieve the aims derived from the conceptual model (e.g. role play exercises to increase HIV-sharing skills; an exercise to enhance helpful thinking about living with HIV to reduce HIV stigma). Exercises were sourced from existing HIV and mental health disclosure interventions (Armistead et al., 2022; Dow et al., 2018; Rusch et al., 2014) as well as being created specifically for this intervention. The intervention was manualised.

Feedback on intervention components was sought from youth with PAH in the UK ($n = 3$) and in Uganda ($n = 10$). All Uganda participants who took part in the interviews described above also took part in the feedback. The three UK participants who took part in the feedback also took part in the interviews. In the UK, we were either unable to reach other potential participants who had been interviewed, or they were unwilling to participate. Documents summarising intervention exercises (e.g. the vignettes and the task for the practising sharing exercise) were presented in individual meetings with the study coordinator. A semi-structured interview guide included questions such as, '*How acceptable do you think this exercise is?',* or '*How confident do you feel that young people with HIV could participate fully in this exercise?'* Participants were reimbursed for their time upon completion.

Ethics

Written consent was sought from all participants. 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, Uganda (JC0319) and Royal Holloway, University of London, UK.

Results

1. *Assessing (a) barriers and facilitators to HIV status-sharing, (b) preferred components of HIV status-sharing interventions, (c) facilitators to involvement in HIV status-sharing intervention studies*

a. Survey

Fifty-seven youth (median age 21 (range 17–28) years; 26 (46%) female) completed the survey. Thirty-six of fifty-seven (63%) agreed or strongly agreed that HIV-sharing was difficult. Twenty one of fifty-seven (37%) were not interested in taking part in a future intervention, 25 (44%) were unsure and 11 (19%) expressed interest. There was no correlation ($r = 0.04$) between perceived HIV-sharing difficulty and interest in a future intervention. Groups (23/57; 40%) and mixed individual and group formats (21/57; 37%) were preferred. Most were keen on mixed gender groups (52/57; 91%) and peer worker involvement both within and outside of the intervention (54/57; 95%). Barriers to HIV-sharing included: Attitudes (e.g. '*I do not want to tell anyone I'm HIV positive*'), normative beliefs (e.g. '*My friends or family would not want me to take part in a course*') and control beliefs (e.g. '*I would not trust other people taking part in the course to keep my HIV status secret*').

b. Semi-structured interviews

Fifty participants were interviewed (25 UK, 25 Uganda). These consisted of 20 participants with PAH (UK: 7 males, 3 females, aged 20–25 years who did not participate in the above survey; Uganda: 3 males, 7 females, aged 22 to 25), 20 social network participants (UK: 3 partner, 1 family, 6 friends; Uganda: 2 partners, 3 family, 5 friends), 10 professionals (UK: Peer support worker, clinical psychologist, nurse, 2 doctors; Uganda – doctor, counsellor, nurse, peer supporter, community liaison worker).

The full findings of the thematic analysis will be reported elsewhere. Key findings across both countries relevant to the development of the intervention included the following:

- Youth and professionals citing the importance of accepting one's status before sharing.
  - '*The young people share their HIV status if they have accepted it at a personal level, they have accepted that am positive but am not bedridden, am HIV positive but am not sick, am positive but I can compete with the non-positive population. So those that accept can find it ok to share*'. Uganda professional
  - '*The reason why I would share my status actually it's because now am confident about who I am, I accepted myself that this is me and I will never change*' Uganda youth with PAH
  - '*Because I found it easier to accept, I feel like ok I'm comfortable with telling people about it*'. UK youth with PAH
- Having support from accepting family or friends helped people living with PAH to feel confident to share with others.
  - '*We have the family back up, wherever the family is backing up that adolescent, he or she will feel free to disclose because he/she knows that she/he will not be blamed by the parents or the family*'. Uganda professional

- Personal values playing a part in whether one wanted to share or not. For example, some youth participants talked about 'honesty' being an important value relevant to sharing. That is, youth not wanting to lie to a friend or partner and feeling guilty about keeping a secret. Family members also reflected on personal values being relevant to the decision to share:

- *'Then the other thing I think just because am her sister, she thought it wise that it was very important for her to share with me'.* Uganda family member

- Friends and partners of youth living with PAH explaining that they had not been educated about HIV until sharing had taken place:
  - *'She made me a booklet with basically everything I need to know…her journey through it, diagrams explaining it all, she told me about U = U … so she made it easy for me. I don't feel like I had any other way to react but to be understanding of it. And like respectful'* UK social network member of youth with PAH

2. *Theory of change*

The conceptual model (see Figure 1) was influenced by the interviews described above. In relation to the interviews, for example, the model specified that the impact of the intervention on the motivation to share one's status would be mediated by reductions in HIV stigma.

Disclosure motivation (attitudes, normative beliefs, self-efficacy, anxiety), disclosure intention and disclosure skills were hypothesised to be important proximal determinants of HIV status-sharing. These proximal factors were suggested to be influenced by more distal factors such as hope and HIV stigma. A single model was generated across both study contexts given the lack of evidence that the determinants of HIV status-sharing are different across settings (even if specific beliefs, for example, anticipated consequences of sharing, may differ). For example, the fear of rejection has been highlighted as a barrier to sharing in low- and high-income contexts (Fernet et al., 2011; Greenhalgh et al., 2016; Zgambo et al., 2021) and in both the Uganda and UK interviews.

3. *Intervention development.*

Feedback on draft intervention.

The draft intervention was revised based on feedback. For example, regarding the personal guidelines exercise, one UK participant stated, *'It might be important at the beginning to lay it out that these rules*

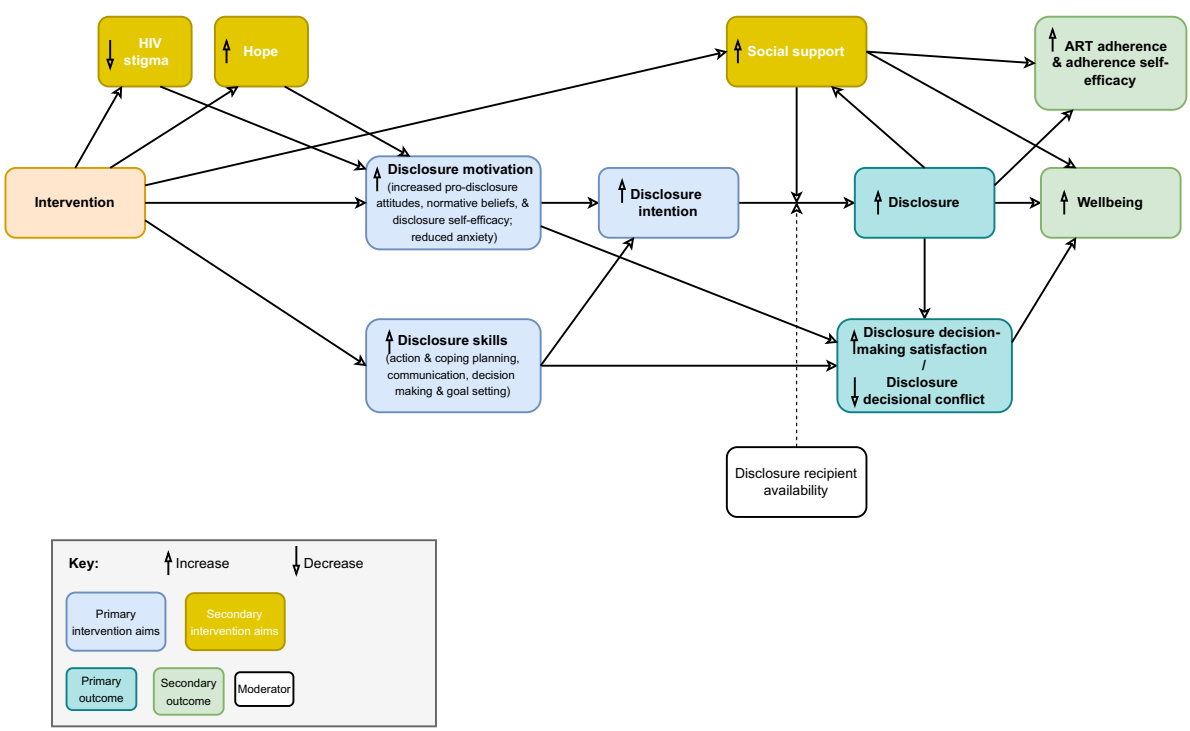

Figure 1. Intervention conceptual model.

aren't permanent and they're not rules that everyone should follow at all times. They're kind of mix and match. And you can change them. I think it's important to note that'. And for the Living with HIV exercise a UK participant stated, *'It's important not to make them too general. It's important to give real life examples of people living with HIV in a positive light and how it's affected them positively - that will help because they'll be like oh these aren't just some bullshit general statements that they're making, these are real people they've spoken to'*. We implemented these and other suggestions.

Overview of intervention.

The intervention comprised four sessions (90 minutes per session) delivered in a mixed group/individual format (3 group/1 individual session), with follow-up support. The individual session (session 4) allowed for the tailoring of goals relevant to participants' specific needs and motivation to change (e.g. partner disclosure may only be relevant to those in a current relationship) (Bachmann et al., 2013). The mixture of individual and group sessions has been used in disclosure interventions focusing on women living with HIV (Bernier et al., 2018; Rochat et al., 2017). The sessions occurred weekly to allow HIV-sharing to take place between sessions.

The groups were mixed gender with a maximum of eight participants in the group sessions. Mixed-gender groups have been used before in a secondary prevention intervention for adolescents living with HIV in Uganda (Nostlinger et al., 2016). The group sessions were led by a health professional (not a trained psychologist) and a peer worker, with either conducting the individual session. The involvement of peer workers is consistent with evidence showing the impact of buddies on HIV disclosure rates (Zuyderduin et al., 2008) and with the use of peer workers in support and ART adherence interventions with young people living with HIV (Ahmed et al., 2023; Mavhu et al., 2020). The decision to deliver the intervention by non-psychologists is consistent with the future potential application to a range of contexts. Therapist training (covering counselling skills, running groups and the intervention) was carried out over eight half days by the first author remotely.

The focus was on sharing with *any* recipient depending on participant preference, as with a disclosure intervention for young men who have sex with men (MSM) (Muessig et al., 2024). It was hypothesised that enhancing sharing with one category of recipient could facilitate sharing with other categories. Increased HIV status-sharing and communication with friends and family has been shown to be associated with sharing with a partner (Weintraub et al., 2017; Wiener & Battles, 2006).

The intervention, consistent with the conceptual model described above, aimed to empower participants to make decisions about HIV-sharing through developing motivation and skills for HIV status-sharing, decrease decisional conflict about HIV-sharing decision-making and increase satisfaction with disclosure decision-making. Secondary aims included increasing hope, decreasing internalised HIV stigma and enhancing social support. Many of the aims were drawn from the interviews described above (e.g. the importance of decreasing HIV stigma and maximising social support). It used a motivational interviewing (MI) *structure* (Miller & Rollnick, 2012). That is, the first session focused on engaging with participants before focusing on HIV-sharing and evoking motivations to share or not to share in session two. It also integrated MI and cognitive behavioural therapy (CBT) *techniques*, and used a range of activities, videos, educational activities and a quiz, as in an intervention with young MSM (Hightow-Weidman et al., 2022). Finally, the intervention was consistent with the *spirit* of MI, for example, supporting participants' autonomy over their decision to share. This feature has been stressed by others who have developed HIV disclosure interventions for youth living with HIV (Muessig et al., 2024). Each session started with a recap and ended with a review of the session and session evaluation. The key characteristics of the intervention were adapted for each study context based on earlier formative work (e.g. the semi-structured interviews), as follows:

1. Creating separate training manuals for each country's therapists with direct quotes from that country's interviews to inform the delivery of intervention exercises (e.g. reasons for sharing or not sharing)
2. Creating separate personal testimony videos for each country that were included in the intervention (i.e. the Uganda intervention included a video of a Uganda youth discussing their experiences of sharing their status)
3. Including discussion of country-specific disclosure laws.
4. Creating separate dramatised videos in session 3, adapted on the basis of country-specific feedback.

The core elements of the intervention, however, were the same in each setting. The intervention was delivered online in the UK (due to Covid restrictions) and in-person in Uganda (which allowed for in-person meetings at the time, despite the Covid pandemic).

Session 1: Engaging

In session one participants were given a workbook to work to accompany session exercises (in English and Luganda for Uganda participants). The first part of the session involved an ice breaker exercise. Participants then engaged in the following exercises:

- Explaining the acronym for HEADS-UP, including defining HIV status-sharing as a *process* (that is, it may take place over time, with further conversations after sharing).
- Establishing group ground rules.
- Eliciting adaptive, accepting beliefs about living with HIV, with the aims of reducing HIV stigma and increasing hope. For this exercise, quotes from participants from the semi-structured interviews described above were also used.
- An exercise titled, '*What you need to know about HIV before sharing?*'. The aim of this exercise was to increase HIV status-sharing skills (action and coping planning) and motivation (self-efficacy). Participants were asked to suggest key information about HIV and, depending on responses, facilitators ensured that material on undetectable equals untransmittable (U = U), PEP, PrEP, HIV and the law, HIV transmission and treatment was provided. Increasing HIV knowledge has been included as a component an HIV disclosure intervention for maternal HIV disclosure (Armistead et al., 2022).
- A personal values clarification exercise. This involved participants rating personal values, such as '*acceptance*' and '*safety*', derived from acceptance and commitment therapy (Harris, 2008; Hayes et al., 2003). Values clarification exercises have also been used in mental health disclosure interventions (Henderson et al., 2012) and in motivational interviewing (Miller & Rollnick, 2012). The aim of this exercise was to use personal values to deepen intrinsic motivation in relation to HIV status-sharing goals elicited in session 4.

Session 2: Focusing and evoking

This session had the following exercises:

- An HIV-sharing quiz, which aimed to increase HIV status-sharing motivation through normalising anxiety about sharing and highlighting potentially positive outcomes of HIV disclosure. This quiz consisted of 10 statements (e.g. '*People's reactions to you telling them that you are living with HIV cannot change over time*' with true/false response options (e.g. '*False – reactions can change from negative to positive over time*'). Potentially negative outcomes and selective sharing were normalised. We are not aware of a quiz format being used in other HIV status-sharing interventions.

- An exercise eliciting reasons for sharing and not sharing an HIV status. Participants were introduced to the concept of personal and social reasons for sharing. Similar exercises have been used in mental health and maternal HIV disclosure interventions (Armistead et al., 2022; Henderson et al., 2012; Rusch et al., 2014). The importance of personal safety in relation to status-sharing was stressed, as well as the concept that motivation to share may depend on the potential recipient. The distinction between *wanting to* versus *needing* to share was made. The aim of the exercise was to normalise ambivalence and anxiety about sharing, while also increasing sharing motivation through highlighting potential health and social motivators and reducing disclosure anxiety. We used direct quotes from that country's interviews to inform the delivery of this exercise.

- An exercise which asked participants to consider helpful things to think and do to manage anxiety about sharing (using cognitive restructuring principles from CBT). Depending on participant responses, Socratic questions were asked (e.g. '*What is the evidence that what I'm worried about is going to happen?*'). The aim of this exercise was to increase sharing motivation through reducing disclosure anxiety.

- Observing a brief film of a youth's experience of sharing their status. Two individuals (one in the UK, one in Uganda) were interviewed about their history of sharing their HIV status while growing up. Participants were asked questions to elicit personal reflection on the film (e.g. '*How was her story similar or different to yours?*'). The aim of the exercise was to elicit hope, normalise disclosure anxiety, model sharing strategies (and thus increase sharing skills) and highlight positive sharing outcomes.
- An exercise on personal sharing guidelines. Participants were asked about the benefits of having personal sharing guidelines (e.g. '*I'll share if I'm serious about someone*'). They were also asked when sharing their status with someone else, what would be the right and the wrong thing to do. The aim of the exercise was to encourage reflection on sharing decision-making (thus improving disclosure goal-setting skills). In addition, the aim was to make decisions about sharing more automatic, consistent with implementation intentions interventions (Gollwitzer & Schaal, 1998). This exercise was a novel feature of interventions for youth living with HIV.

Session 3: Sharing skills
This session had the following exercises:

- An exercise focused on a filmed fictional three act mini drama created for the intervention (shot separately with UK and Ugandan actors for each country) (see Figure 2).

A script was developed in collaboration with youth living with PAH. Act one showed a male youth with PAH expressing fears about sharing their HIV status with their female partner. In act two, the HIV status is shared. In the final act, one week later, the couple talk about the male's HIV status and the impact on both partners. The participants are asked questions based on the film, such as '*How different is the situation in the film from sharing with a friend?*' with responses summarised. The idea of using a film to facilitate discussion around HIV status-sharing was based on the premise that it would be easier to engage youth in watching and answering questions based on a drama than in asking directly about their experiences. The film aimed to create empathy with both partners through providing realistic representations of their concerns, the HIV-sharing itself and its aftermath. We also wanted to model a possible, helpful way that youth living with HIV could share their HIV status. The exercise also aimed to normalise sharing anxiety and the process of sharing, to model a clear way that HIV status could be shared and to show a realistic but positive outcome. The importance of showing that recipients' responses can change from negative to positive over time has been emphasised by other authors (Geubbels et al., 2018). The script was informed by social cognitive theory (Bandura, 1986). The importance of eliciting empathy in health promotion

Figure 2. Filmed fictional mini drama.

activities has been stressed by other authors (Campbell & Babrow, 2004). The exercise aimed to increase disclosure motivation and skills (action and coping planning). We are not aware of other HIV-sharing interventions using a similar exercise.

- An exercise on planning to share if a decision has been made to share. This exercise covered *action* planning (when, where and how to share) and *coping* planning (strategies to manage barriers to sharing) (Sniehotta et al., 2005). This exercise used material from a previous mental health intervention for youth living with HIV (Dow et al., 2018). Suggestions were elicited from participants and additional strategies were offered (e.g. '*Consider what you want to tell this person and how they may react*', '*Learn a way to tell your story in a personally meaningful way – use "me", "my", "I" and "HIV"*'). The group were then asked what would be helpful to think about and to do after sharing if they got no reaction, or a negative reaction from the person they had told. Talking the action and coping plan through with someone trusted was suggested, as well as practicing in one's mind or with someone who already knew their status. The aim of the exercise was to enhance HIV disclosure skills and self-efficacy.
- A role-play exercise to practice sharing. Participants were encouraged to gain experience in dealing with different responses and practicing a way of sharing that they feel comfortable with (based on vignettes that they could choose). The aims of this exercise were to enhance HIV disclosure skills and self-efficacy. Role play strategies have been used in other HIV disclosure interventions for adults living with HIV (Armistead et al., 2022; Serovich et al., 2020).

Session 4.

Session four was an individual session, aimed at helping the participant to develop a sharing goal and plan of how to achieve this goal using a sharing platform. This approach has been used in a mental health disclosure intervention (Rusch et al., 2014). First, the participants were asked to generate a sharing goal (e.g. sharing to a particular person). Then, they were asked the reason for this goal. Next, they were asked how this reason related to their personal values (elicited in session one) and personal sharing guidelines. The aim of this approach was to deepen intrinsic motivation to share. The next step was to develop (a) an action plan for achieving the goal, including *when, where* and *how* to share and *what to say* and (b) a 'coping plan' for how to manage barriers for sharing. The session ended with the therapist ensuring the participant was content with their goal and plan. The aim of this session was to enhance motivation (commitment, in particular) to HIV-sharing, as well as disclosure skills (action and coping planning, decision-making and goal setting). The approach of this session was based on both implementation intentions (Gollwitzer & Schaal, 1998) and acceptance and commitment therapy (Hayes et al., 2003). The participants were encouraged to keep a copy of their plan to refer to in the future.

Follow-up support.

In the six months from baseline to the follow-up data point, the peer worker therapist provided follow-up emotional, informational and problem-solving support for both the youth exposed to the intervention and the people whom they had shared their status with. The participants were offered the opportunity to contact the peer worker via phone, email, or text if any issues arose relating to HIV status-sharing. Guidance was offered to therapists in relation to common anticipated requests for support (e.g. The youth has told someone, and that person has told someone else without their permission). The elicit-provide-elicit approach from motivational interviewing was suggested to guide these conversations (Miller & Rollnick, 2012) as well as the use of open questions, affirmation, reflection and summaries.

Discussion

We aimed to develop an HIV-sharing intervention for youth living with PAH across two contexts that was both based on intensive stakeholder engagement and consistent with empirical and theoretical literature. We used a variety of methods to develop the intervention, including semi-structured interviews with key stakeholders, a survey, the development of an intervention conceptual model and gaining feedback on draft intervention components. We hypothesised that supporting HIV status-sharing decision-making was likely to need more than a very brief (single session) intervention based on the findings from existing interventions and given the extent of HIV disclosure barriers for youth with HIV. Delivering the intervention

in a predominantly group format is more feasible in low-income contexts (Nakimuli-Mpungu et al., 2021) and maximises the potential impact of group support, positive group norms, HIV status-sharing modelling and the efficiency of information exchange.

The survey showed that group and mixed individual and group formats were preferred. Most participants were keen on mixed gender groups and peer worker involvement both within and outside of the intervention. The interviews highlighted the importance of overcoming feelings of shame and accepting one's status before sharing, having support to feel confident to share. These findings are consistent with existing literature (Mugo et al., 2021). Personal values played a part in whether one wanted to share or not. Friends and partners of youth living with HIV explaining that they had not been educated about HIV until someone had shared their status with them. These features, along with specific feedback on draft intervention components were implemented in the final version of the intervention.

The final intervention had many features that we believe are novel for HIV status-sharing interventions for youth living with HIV (Conserve et al., 2015; Kennedy et al., 2015). These include the motivational interviewing structure, personal sharing guidelines, the focus on personal values (and values-consistent goals), the development of separate video dramas for each context that aimed to elicit empathy and encourage reflection and the use of goal setting and planning proforma using implementation intentions principles. In addition, specific material from the interviews was used to contextualise the intervention in both countries. The intervention is most generalisable to youth living with perinatally acquired HIV, but we suggest that some features are relevant to youth and adults of a working age living with HIV regardless of the route of infection.

A strength of the intervention development process included consideration of implementation issues from the outset, for example, choosing peers and staff as therapists, whose capacity could be built through teaching skills that could be used in other work. In addition, we made considerable effort in creating a programme that was relevant to each study context. When designing the intervention, we hypothesised that four sessions was the shortest number of sessions to explore the inherent ambivalence associated with HIV-sharing in a way that was supportive. We continue to believe that this is the case, based on carrying out the feasibility trial that took place after the intervention development process (Evangeli et al., 2024; O'Keeffe et al., 2025). It may be, however, that the final session can be used as a stand-alone intervention if someone is ready to share. A further strength was the diverse nature of the research team in relation to professional background, region, demographics and training, with considerable professional and clinical experience relating to HIV status-sharing. The survey that we undertook provided useful information on preferred features of the intervention and potential barriers to participation.

Limitations of the intervention development process included the fact that we did not follow recommended theory of change strategies in full. For example, we did not hold an interactive stakeholder workshop (Maini et al., 2018). Rather, the conceptual model was developed by a research team, informed by the individual stakeholder interviews. There are some potential limitations with the conceptual model itself. For example, it could be that HIV knowledge (targeted in session one) is an important mediator of change. Further limitations include that the initial survey was only carried out in the UK and the wider age range in the UK. In addition, the survey did not capture individual barriers and facilitators to HIV status-sharing, sampling was not representative or purposive, response rates were unknown and no a priori power calculation was carried out before the survey.

Future work on the intervention could involve carrying out both outcome and process evaluations, including testing hypothesised change mechanisms, which should be carried out alongside ongoing consideration of sustainability and implementation issues (e.g. how to integrate the intervention with existing health systems/processes and scale up the intervention). The evaluation should consider which aspects of the intervention are core and which components can be modified and adapted according to the context. Similarities and differences in the acceptability, feasibility and effectiveness of the intervention between contexts should be assessed.

The practice implications of the intervention development work described in this article require further clarification. For example, it is not clear if the sample who were recruited for this work were representative of the population that they were drawn from. Nevertheless, we were able to recruit a relatively large number of participants, which is likely to have resulted in a broad range of views reflected in the content of the intervention. This *may* mean that individual exercises or the overall intervention approach taken could be used with minimal adaptation is some contexts. This could be particularly valuable in contexts where minimal HIV status-sharing support is offered.

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Data availability statement

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

Consent to participate and publish

Written consent was sought from participants.

References

Abramowitz, S., Koenig, L. J., Chandwani, S., Orban, L., Stein, R., Lagrange, R., & Barnes, W. (2009). Characterizing social support: Global and specific social support experiences of HIV-infected youth. *AIDS Patient Care and STDs*, *23*(5), 323–330. https://doi.org/10.1089/apc.2008.0194

Ahmed, C. V., Doyle, R., Gallagher, D., Imoohi, O., Ofoegbu, U., Wright, R., Yore, M. A., Brooks, M. J., Flores, D. D., Lowenthal, E. D., Rice, B. M., & Buttenheim, A. M. (2023). A systematic review of peer support interventions for adolescents living with HIV in sub-saharan Africa. *AIDS Patient Care and STDs*, *37*(11), 535–559. https://doi.org/10.1089/apc.2023.0094

Armistead, L., Marelich, W. D., Murphy, D. A., Schulte, M. T., Goodrum, N., & Kim, S. (2022). Implementing a multisite efficacy trial to facilitate maternal disclosure to children: The TRACK HIV disclosure intervention. *Translational Behavioral Medicine*, *12*(5), 630–641. https://doi.org/10.1093/tbm/ibab167

Bachmann, L. H., Grimley, D. M., Gao, H., Aban, I., Chen, H., Raper, J. L., Saag, M. S., Rhodes, S. D., & Hook, E. W. (2013). Impact of a Computer-Assisted, Provider-Delivered Intervention on Sexual Risk Behaviors in HIV-Positive Men Who Have Sex With Men (MSM) in a Primary Care Setting. AIDS Education and Prevention, 25(2), 87–101. https://doi.org/10.1521/aeap.2013.25.2.87

Bakeera-Kitaka, S., Nabukeera-Barungi, N., Nostlinger, C., Nöstlinger, C., Addy, K., & Colebunders, R. (2008). Sexual risk reduction needs of adolescents living with HIV in a clinical care setting. *AIDS Care*, *20*(4), 426–433. https://doi.org/10.1080/09540120701867099

Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Prentice Hall.

Becker, G., Namanya, P., Kiganda, C., Nabukenya, J., Wendt, L., Rukundo, G., Yoyeta, I., Motevalli, M., Mooberry, M., Voss, N., Jackson, J. B., & Etima, J. (2024). HIV knowledge and sexual behaviors in perinatally infected Ugandan youth: A cross-sectional survey. *Journal of the International Association of Providers of AIDS Care*, *23*, 23259582241299712. https://doi.org/10.1177/23259582241299712

Bernays, S., Paparini, S., Gibb, D., & Seeley, J. (2016). When information does not suffice: young people living with HIV and communication about ART adherence in the clinic. Vulnerable Children and Youth Studies, 11(1), 60–68. https://doi.org/10.1080/17450128.2015.1128581

Bernier, A., Yattassaye, A., Beaulieu-Prevost, D., Beaulieu-Prévost, D., Otis, J., Henry, E., Flores-Aranda, J., Massie, L., Préau, M., & Keita, B. D. (2018). Empowering Malian women living with HIV regarding serostatus disclosure management: Short-term effects of a community-based intervention. *Patient Education and Counseling*, *101*(2), 248–255. https://doi.org/10.1016/j.pec.2017.07.030

Boon-Yasidhi, V., Torsakul, S., Durier, Y., Sittanomai, N., Kuntasorn, J., & Chokephaibulkit, K. (2021). Disclosure of HIV status to sexual partners among perinatally HIV-infected youth in Thailand. *International Journal of STD & AIDS*, *32*(4), 361–367. https://doi.org/10.1177/0956462420968405

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), S5–16. https://doi.org/10.1080/02664763.2012.755319

Braun, V., & Clarke, V. (2019). Novel insights into patients' life-worlds: The value of qualitative research. *The Lancet Psychiatry*, *6*(9), 720–721. https://doi.org/10.1016/S2215-0366(19)30296-2

Brown, M. J., Serovich, J. M., Laschober, T. C., Kimberly, J. A., & Lescano, C. M. (2019). Mediating effects of depressive symptoms on perceived social support and HIV disclosure: Assessing moderation by sex. *AIDS and Behavior*, *23*(3), 636–648. https://doi.org/10.1007/s10461-018-2369-x

Buchanan, A. L., Montepiedra, G., Sirois, P. A., Kammerer, B., Garvie, P. A., Storm, D. S., & Nichols, S. L. (2012). Barriers to medication adherence in HIV-infected children and youth based on self- and caregiver report. *Pediatrics*, *129*(5), e1244–1251. https://doi.org/10.1542/peds.2011-1740

Campbell, R. G., & Babrow, A. S. (2004). The role of empathy in responses to persuasive risk communication: Overcoming resistance to HIV prevention messages. *Health Communication*, *16*(2), 159–182. https://doi.org/10.1207/S15327027HC1602_2

Chaudoir, S. R., Fisher, J. D., & Simoni, J. M. (2011). Understanding HIV disclosure: A review and application of the disclosure processes model. *Social Science & Medicine*, *72*(10), 1618–1629. https://doi.org/10.1016/j.socscimed.2011.03.028

Conserve, D. F., Groves, A. K., & Maman, S. (2015). Effectiveness of interventions promoting HIV serostatus disclosure to sexual partners: A systematic review. *AIDS and Behavior*, *19*(10), 1763–1772. https://doi.org/10.1007/s10461-015-1006-1

De Silva, M. J., Breuer, E., Lee, L., Asher, L., Chowdhary, N., Lund, C., & Patel, V. (2014). Theory of change: A theory-driven approach to enhance the medical research Council's framework for complex interventions. *Trials*, *15*, 267. https://doi.org/10.1186/1745-6215-15-267

Dessie, G., Wagnew, F., Mulugeta, H., Amare, D., Jara, D., Leshargie, C. T., Negesse, A., Rayasam, S., & Burrowes, S. (2019). The effect of disclosure on adherence to antiretroviral therapy among adults living with HIV in Ethiopia: A systematic review and meta-analysis. *BMC Infectious Diseases*, *19*(1), 528. https://doi.org/10.1186/s12879-019-4148-3

Dlamini, B. P., & Mtshali, N. G. (2023a). Views of adolescents living with perinatally acquired HIV on HIV status disclosure in eswatini. *AIDS Care*, 36(9), 1–9. https://doi.org/10.1080/09540121.2023.2299334

Dlamini, B. P., & Mtshali, N. G. (2023b). We will tell when we are ready: Perinatally HIV-infected adolescents and self-disclosure of their status in eswatini. *African Journal of AIDS Research*, 22(3), 1–9. https://doi.org/10.2989/16085906.2023.2266406

Dow, D. E., Mmbaga, B. T., Turner, E. L., Gallis, J. A., Tabb, Z. J., Cunningham, C. K., & O'Donnell, K. E. (2018). Building resilience: A mental health intervention for Tanzanian youth living with HIV. *AIDS Care*, *30*(sup4), 12–20. https://doi.org/10.1080/09540121.2018.1527008

Enane, L. A., Apondi, E., Toromo, J., Bosma, C., Ngeresa, A., Nyandiko, W., & Vreeman, R. C. (2020). "A problem shared is half solved" - A qualitative assessment of barriers and facilitators to adolescent retention in HIV care in Western Kenya. *AIDS Care*, *32*(1), 104–112. https://doi.org/10.1080/09540121.2019.1668530

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), S343–346. https://doi.org/10.1097/QAD.0000000000000334

Evangeli, M., & Kagee, A. (2016). A model of caregiver paediatric HIV disclosure decision-making. *Psychology, Health & Medicine*, *21*(3), 338–353. https://doi.org/10.1080/13548506.2015.1058959

Evangeli, M., & Wroe, A. L. (2017). HIV disclosure anxiety: A systematic review and theoretical synthesis. *AIDS and Behavior*, *21*(1), 1–11. https://doi.org/10.1007/s10461-016-1453-3

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

Fernet, M., Wong, K., Richard, M. E., Otis, J., Lévy, J. J., Lapointe, N., Samson, J., Morin, G., Thériault, J., & Trottier, G. (2011). Romantic relationships and sexual activities of the first generation of youth living with HIV since birth. *AIDS Care*, *23*(4), 393–400. https://doi.org/10.1080/09540121.2010.516332

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

Galano, E., Turato, E. R., Succi, R. C., de Souza Marques, H. H., Della Negra, M., da Silva, M. H., do Carmo, F. B., Gouvea, A., Delmas, P., Côté, J., & Machado, D. M. (2017). Costs and benefits of secrecy: The dilemma experienced by adolescents seropositive for HIV. *AIDS Care*, *29*(3), 394–398. https://doi.org/10.1080/09540121.2016.1248891

Geubbels, E., Williams, A., Ramaiya, A., Tancredi, D., Young, S., & Chantry, C. (2018). HIV status disclosure among postpartum women in rural Tanzania: Predictors, experiences and uptake of a nurse-facilitated disclosure intervention. *AIDS Care*, *30*(4), 417–425. https://doi.org/10.1080/09540121.2018.1428724

Glenn, J. S., Bennett, A., Mackie, N., Lyall, H., Fidler, S., Taylor, G., & Foster, C. (2025). The cumulative prevalence of HIV-1 drug resistance in perinatal HIV. *AIDS*, *39*, 1161–1177. https://doi.org/10.1097/QAD.0000000000004202

Gollwitzer, P. M., & Schaal, B. (1998). Metacognition in action: The importance of implementation intentions. *Personality and Social Psychology Review*, *2*(2), 124–136. https://doi.org/10.1207/s15327957pspr0202_5

Greene, K. (2009). An integrated model of health disclosure decision-making. In Afifi T. D., & Afifi W. A. (Eds.), *Uncertainty and information regulation in interpersonal contexts: Theories and applications* (pp. 226–253). Routledge.

Greenhalgh, C., Evangeli, M., Frize, G., Foster, C., & Fidler, S. (2013). Intimate relationships in young adults with perinatally acquired HIV: Partner considerations. *AIDS Care*, *25*(4), 447–450. https://doi.org/10.1080/09540121.2012.712671

Greenhalgh, C., Evangeli, M., Frize, G., Foster, C., & Fidler, S. (2016). Intimate relationships in young adults with perinatally acquired HIV: A qualitative study of strategies used to manage HIV disclosure. *AIDS Care*, *28*(3), 283–288. https://doi.org/10.1080/09540121.2015.1093594

Harris, R. (2008). *The happiness trap*. Little.

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (2003). *Acceptance and commitment therapy: An experiential approach to behavior change*. Guilford.

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.

Henderson, C., Brohan, E., Clement, S., Williams, P., Lassman, F., Schauman, O., Murray, J., Murphy, C., Slade, M., & Thornicroft, G. (2012). A decision aid to assist decisions on disclosure of mental health status to an employer: Protocol for the CORAL exploratory randomised controlled trial. *BMC Psychiatry*, *12*, 133. https://doi.org/10.1186/1471-244X-12-133

Hightow-Weidman, L. B., Muessig, K., Soberano, Z., Rosso, M. T., Currie, A., Adams Larsen, M., Knudtson, K., & Vecchio, A. (2022). Tough talks virtual simulation HIV disclosure intervention for young men who have sex with men: Development and usability testing. *JMIR Formative Research*, *6*(9), e38354. https://doi.org/10.2196/38354

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

Hult, J. R., Wrubel, J., Bränström, R., Acree, M., & Moskowitz, J. T. (2012). Disclosure and Nondisclosure Among People Newly Diagnosed with HIV: An Analysis from a Stress and Coping Perspective. AIDS Patient Care and STDs, 26(3), 181–190. https://doi.org/10.1089/apc.2011.0282

Izudi, J., Okoboi, S., Lwevola, P., Kadengye, D., Bajunirwe, F., & Donnell, D. (2021). Effect of disclosure of HIV status on patient representation and adherence to clinic visits in eastern Uganda: A propensity-score matched analysis. *PLoS One*, *16*(10), e0258745. https://doi.org/10.1371/journal.pone.0258745

Kajubi, P., Katahoire, A. R., Kyaddondo, D., & Whyte, S. R. (2016). Communication in the Context of Family Caregiving: An Exploratory Study of Ugandan Children on Antiretroviral Therapy. Journal of Biosocial Science, 48(5), 672–693. https://doi.org/10.1017/S0021932015000371

Kaplowitz, M. D. (2000). Statistical analysis of sensitive topics in group and individual interviews. *Quality and Quantity*, *34*, 419–431. https://doi.org/10.1023/A:1004844425448

Kennedy, C. E., Fonner, V. A., Armstrong, K. A., O'Reilly, K. R., & Sweat, M. D. (2015). Increasing HIV serostatus disclosure in low and middle-income countries: A systematic review of intervention evaluations. *AIDS*, *29*(Suppl 1), S7–S23. https://doi.org/10.1097/QAD.0000000000000671

Maini, R., Mounier-Jack, S., & Borghi, J. (2018). How to and how not to develop a theory of change to evaluate a complex intervention: Reflections on an experience in the democratic Republic of Congo. *BMJ Global Health*, *3*(1), e000617. https://doi.org/10.1136/bmjgh-2017-000617

Mavhu, W., Willis, N., Mufuka, J., Bernays, S., Tshuma, M., Mangenah, C., Maheswaran, H., Mangezi, W., Apollo, T., Araya, R., Weiss, H. A., & Cowan, F. M. (2020). Effect of a differentiated service delivery model on virological failure in adolescents with HIV in Zimbabwe (Zvandiri): A cluster-randomised controlled trial. *The Lancet Global Health*, *8*(2), e264–e275. https://doi.org/10.1016/S2214-109X(19)30526-1

McGray, T., Ondeng, K., Sabben, G., McGray, T. L., Ondeng'e, K., Clevenger, E., Lando, R., Mbeda, C., Opollo, V., & Winskell, K. (2023). You are not alone' - the role of social relationships in engagement in care for adolescents living with perinatally acquired HIV in Western Kenya. *SSM Qualitative Research in Health*, *4*, 100331. https://doi.org/10.1016/j.ssmqr.2023.100331

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*, 18593. https://doi.org/10.7448/IAS.16.1.18593

Mi, T., Li, X., Zhou, G., Qiao, S., & Shen, Z. (2020). HIV disclosure to family members and medication adherence: Role of social support and self-efficacy. *AIDS and Behavior*, *24*(1), 45–54. https://doi.org/10.1007/s10461-019-02456-1

Miller, W. R., & Rollnick, S. (2012). *Motivational Interviewing, Third Edition: Helping People Change*. Guilford.

Muessig, K. E., Vecchio, A. C., Hanshaw, B. D., Soberano, Z., Knudtson, K. A., Claude, K. F., Larsen, M. A., & Hightow-Weidman, L. B. (2024). Barriers, facilitators and opportunities for HIV status disclosure among young men who have sex with men: Qualitative findings from the tough talks intervention. *AIDS and Behavior*, *28*, 3283–3299. https://doi.org/10.1007/s10461-024-04406-y

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

Murphy, D. A., Roberts, K. J., Hoffman, D., Johnston Roberts, K., Molina, A., & Lu, M. C. (2003). Barriers and successful strategies to antiretroviral adherence among HIV-infected monolingual spanish-speaking patients. *AIDS Care*, *15*(2), 217–230. https://doi.org/10.1080/0954012031000068362

Mwanza-Kabaghe, S., Sportiello, K., & Shah, M., et al. (2025). Executive function and adherence in children and adolescents living with HIV: Evidence from the HIV-associated neurocognitive disorders in Zambia (HANDZ) study. Journal of Child Neurology, 8830738251360197. https://doi.org/10.1177/08830738251360197

Nakimuli-Mpungu, E., Musisi, S., Smith, C. M., Nakimuli-Mpungu, E., Von Isenburg, M., Akimana, B., Shakarishvili, A., Nachega, J. B., Mills, E. J., Chibanda, D., Ribeiro, M., V Williams, A., & Joska, J. A. (2021). Mental health interventions for persons living with HIV in low- and middle-income countries: A systematic review. *Journal of the International AIDS Society*, *24*(Suppl 2), e25722. https://doi.org/10.1002/jia2.25722

Nawfal, E. S., Gray, A., Sheehan, D. M., Ibañez, G. E., & Trepka, M. J. (2024). A systematic review of the impact of HIV-Related stigma and serostatus disclosure on retention in care and antiretroviral therapy adherence among women with HIV in the United States/Canada. *AIDS Patient Care STDS*, *38*(1), 23–49. https://doi.org/10.1089/apc.2023.0178

Nostlinger, C., Bakeera-Kitaka, S., Buyze, J., Nöstlinger, C., Loos, J., & Buvé, 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

Nostlinger, C., Loos, J., Bakeera-Kitaka, S., Nöstlinger, C., Jasna, L., Sabrina, B., Obong'o, C., Eric, W., & Buvé, A. (2016). Translating primary into 'positive' prevention for adolescents in Eastern Africa. *Health Promotion International*, *31*(3), 653–664. https://doi.org/10.1093/heapro/dav044

Ojwang, V. O., Penner, J., Blat, C., Agot, K., Bukusi, E., & Cohen, C. (2016). Loss to follow-up among youth accessing outpatient HIV care and treatment services in kisumu, Kenya. *AIDS Care*, *28*(4), 500–507. https://doi.org/10.1080/09540121.2015.1110234

O'Keeffe, A., Price, J., & Seeley, J. (2025). 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. *AIDS Care*, 1–12. https://doi.org/10.1080/09540121.2025.2482672

Patel, K., Seage, G. R., 3rd, Burchett, S. K., Hazra, R., & Van Dyke, R. B. (2019). Disparities in HIV viral suppression among adolescents and young adults by perinatal infection. *American Journal of Public Health*, *109*(7), e9–e9. https://doi.org/10.2105/AJPH.2019.305108

Rakhmanina, N., Foster, C., & Agwu, A. (2024). Adolescents and young adults with HIV and unsuppressed viral load: Where do we go from here? *Current Opinion in HIV and AIDS*, *19*(6), 368–376. https://doi.org/10.1097/COH.0000000000000880

Rochat, T. J., Mkwanazi, N., & Bland, R. (2013). Maternal HIV disclosure to HIV-uninfected children in rural South Africa: A pilot study of a family-based intervention. *BMC Public Health*, *13*, 147. https://doi.org/10.1186/1471-2458-13-147

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

Rotheram-Borus, M. J., Lee, M. B., & Murphy, D. A., et al. (2001). Efficacy of a preventive intervention for youths living with HIV. *American Journal of Public Health*, *91*(3), 400–405.

Rusch, N., Abbruzzese, E., Hagedorn, E., Rüsch, N., Hartenhauer, D., Kaufmann, I., Curschellas, J., Ventling, S., Zuaboni, G., Bridler, R., Olschewski, M., Kawohl, W., Rössler, W., Kleim, B., & Corrigan, P. W. (2014). Efficacy of coming out proud to reduce stigma's impact among people with mental illness: Pilot randomised controlled trial. *British Journal of Psychiatry*, *204*(5), 391–397. https://doi.org/10.1192/bjp.bp.113.135772

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

Skivington, K., Matthews, L., Simpson, S. A., Craig, P., Baird, J., Blazeby, J. M., Boyd, K. A., French, D. P., McIntosh, E., Petticrew, M., Rycroft-Malone, J., White, M., & Moore, L. (2021). Framework for the development and evaluation of complex interventions: Gap analysis, workshop and consultation-informed update. *Health Technology Assessment*, *25*(57), 1–132. https://doi.org/10.3310/hta25570

Smith, T., Seeley, J., Shahmanesh, M., Psaros, C., Munikwa, C., & Ngwenya, N. (2023). Influences on decision-making about disclosure of HIV status by adolescents and young adults living with HIV in KwaZulu-Natal, South Africa. *African Journal of AIDS Research*, *22*(4), 306–315. https://doi.org/10.2989/16085906.2023.2277358

Sniehotta, F. F., Scholz, U., Schwarzer, R., Fuhrmann, B., Kiwus, U., & Völler, H. (2005). Long-term effects of two psychological interventions on physical exercise and self-regulation following coronary rehabilitation. *International Journal of Behavioral Medicine*, *12*(4), 244–255. https://doi.org/10.1207/s15327558ijbm1204_5

Snyder, K., Wallace, M., Duby, Z., Aquino, L. D., Stafford, S., Hosek, S., Futterman, D., & Bekker, L. (2014). Preliminary results from hlanganani (coming together): A structured support group for HIV-infected adolescents piloted in Cape Town, South Africa. *Children and Youth Services Review*, *45*, 114–121. https://doi.org/10.1016/j.childyouth.2014.03.027

Sohn, A. H., & Davies, M. A. (2024). Adults with perinatally acquired HIV in low- and middle-income settings: Time for a generational shift in HIV care and global guidance. *Journal of the International AIDS Society*, *27*(7), e26338. https://doi.org/10.1002/jia2.26338

Thoth, C. A., Tucker, C., Leahy, M., & Stewart, S. M. (2013). Self-disclosure of serostatus by youth who are HIV-positive: A review. *Journal of Behavioral Medicine*, *37*, 276–288. https://doi.org/10.1007/s10865-012-9485-2

Too, E. K., Abubakar, A., Nasambu, C., Koot, H. M., Cuijpers, P., Newton, C. R., & Nyongesa, M. K. (2021). Prevalence and factors associated with common mental disorders in young people living with HIV in sub-saharan Africa: A systematic review. *Journal of the International AIDS Society*, *24*(Suppl 2), e25705. https://doi.org/10.1002/jia2.25705

UNAIDS. (2023). HIV and adolescent girls and young women.

Watson-Jones, D., Balira, R., Ross, D. A., Weiss, H. A., Mabey, D., & Vermund, S. H. (2012). Missed opportunities: Poor linkage into ongoing care for HIV-positive pregnant women in mwanza, Tanzania. *PLoS One*, *7*(7), e40091. https://doi.org/10.1371/journal.pone.0040091

Weintraub, A., Mellins, C. A., Warne, P., Dolezal, C., Elkington, K., Bucek, A., Leu, C., 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

Whembolua, G. L., Conserve, D. F., Thomas, K., & Handler, L. (2016). A systematic review of HIV serostatus disclosure among African immigrants in Europe. *Journal of Immigrant and Minority Health*, *19*, 947–958. https://doi.org/10.1007/s10903-016-0456-5

WHO. (2014). *Health for the world's adolescents: A second chance in the second decade*. World Health Organization.

WHO. (2018). *WHO recommendations on adolescent sexual and reproductive health and rights*. World Health Organization.

Wiener, L. S., & Battles, H. B. (2006). Untangling the web: A close look at diagnosis disclosure among HIV-infected adolescents. *Journal of Adolescent Health*, *38*(3), 307–309. https://doi.org/10.1016/j.jadohealth.2005.03.024

Wight, D., Wimbush, E., Jepson, R., & Doi, L. (2016). Six steps in quality intervention development (6SQuID). *Journal of Epidemiology and Community Health*, *70*(5), 520–525. https://doi.org/10.1136/jech-2015-205952

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

Zuyderduin, J. R., Ehlers, V. J., & van der Wal, D. M. (2008). The impact of a buddy system on the self-care behaviours of women living with HIV/AIDS in Botswana. *Health SA Gesonheid*, *13*, 4–15. https://doi.org/10.4102/hsag.v13i4.400