**Intimate relationships in young adults with perinatally acquired HIV: a qualitative study of strategies used to manage HIV disclosure.**

Clare Greenhalgh[[1]](#footnote-1), Michael Evangeli[[2]](#footnote-2)1, Graham Frize[[3]](#footnote-3)2, Caroline Foster[[4]](#footnote-4)2, Sarah Fidler[[5]](#footnote-5)2

**RESEARCH ARTICLE**

**ABSTRACT**

An increasing number of children born with perinatally-acquired HIV (PAH) are surviving into late adolescence and early adulthood. At this developmental stage, forming and sustaining intimate relationships is important. Young adults with PAH face both normative challenges and additional, HIV-related, relationship stressors. One key issue is the decision about whether and how to share their HIV status with others. Being able to disclose one’s HIV status to sexual partners may reduce the risk of onward HIV transmission but is associated with the fear of rejection. There has been little research on how young people with PAH manage such disclosure-related stressors in intimate relationships. This study examined how disclosure challenges are managed by young adults with PAH in the UK within their intimate relationships. Seven participants (five females, two males) currently or previously in an intimate relationship, aged 18-23 years, were recruited from a UK hospital clinic. The majority of participants were of sub-Saharan African origins. They took part in in-depth interviews, with data analysed according to the principles of Interpretative Phenomenological Analysis (IPA). Four themes were elicited: (1) Decisions about starting, continuing or resuming relationships shaped by disclosure (2) Disclosing early to avoid the pain of future rejection (3) Using condoms to avoid disclosure (4) Testing likely partner reactions to disclosure. The study revealed the significant extent to which HIV disclosure affected the experience of relationships in this population. Interventions to support adolescents and young adults with PAH to disclose to their partners should be developed alongside guidance for professionals. Future research should include older samples of adults with PAH and studies in sub-Saharan African settings.

**Key words: HIV, perinatally acquired, young adults, disclosure**

**INTRODUCTION**

Enhanced availability of antiretroviral therapy (ART) for children has improved survival for individuals with perinatally-acquired HIV (PAH). Within the UK around 50% of those with PAH are now aged ≥15 years ([CHIPS, 2014](#_ENREF_6)).

The stressors faced by young adults with PAH include those experienced by HIV-positive individuals irrespective of transmission route (e.g., potentially compromised health and risk of onward transmission through sex and perinatally) ([Mellins & Malee, 2013](#_ENREF_17)). Other stressors relate specifically to perinatal transmission including; having to consider sexual risk reduction and onward HIV disclosure in intimate relationships *from their onset*, adjusting to being HIV-positive from childhood, and living in a family with other member living with HIV ([Evangeli & Foster, 2014](#_ENREF_10); [Mellins & Malee, 2013](#_ENREF_17)). A young person with PAH who shares their status also potentially discloses the status of their mother (and possibly siblings and father). Young adults with HIV face additional normative developmental challenges concerning relationships and sexuality ([Wiener, Battles, & Wood, 2007](#_ENREF_22)).

Studies with adolescents and young adults with PAH have shown low rates of HIV disclosure to partners. Birungi et al ([Birungi, Obare, Mugisha, Evelia, & Nyombi, 2009](#_ENREF_3)) reported that only 38% of their sample of youth with PAH in relationships (aged 15 to 19 years) had disclosed their HIV status to their current partner. The association between HIV disclosure and sexual behaviour is complex. High rates of unprotected sex amongst those with PAH who are sexually active have been reported ([Tassiopoulos et al., 2013](#_ENREF_20)), although there is no evidence that rates are higher than in HIV negative comparison groups.

A small number of studies have examined the experiences of intimate relationships in children (≤16 years) with PAH qualitatively ([Campbell et al., 2010](#_ENREF_5); [Fernet et al., 2007](#_ENREF_13); [Fielden et al., 2006](#_ENREF_14); [Marhefka et al., 2011](#_ENREF_16)). Themes elicited include the subjective difficulty of onward HIV disclosure. Marked concerns have been reported about the potential impact of disclosure on the continuation of relationships, including fear of negative reactions from partners, rejection and stigmatisation. More recently, qualitative studies have examined aspects of intimate relationships in young *adults* with PAH, including partner perceptions ([Greenhalgh, Evangeli, Frize, Foster, & Fidler, 2013](#_ENREF_15)) and parenting considerations ([Evangeli, Greenhalgh, Frize, Foster, & Fidler, 2014](#_ENREF_11)). One US study ([Fair & Albright, 2012](#_ENREF_12)) also focused on the experience of intimate relationships in young adults (mean age 21 years) with PAH. Many participants in this study had experienced rejection when disclosing their HIV status to partners. Some individuals, however, had never disclosed to partners and reported a range of strategies to manage intimacy, including delaying dating, terminating relationships and ‘taking it slow’.

The current study filled a gap in the literature by examining how young adults with PAH in the UK negotiate disclosure challenges in their intimate relationships. The UK population of young adults with PAH is distinct from the US population (where most studies have taken place) in being largely of sub-Saharan African origins with a significant proportion born overseas ([CHIPS, 2014](#_ENREF_6)).

**METHOD**

**Design and setting**

The study used a qualitative cross-sectional design with in-depth semi-structured interviews. Participants were recruited from a multidisciplinary London National Health Service (NHS) clinic for 16-25 year olds, with a caseload of approximately 65 individuals with PAH.

**Participants**

Inclusion criteria were that individuals had perinatally-acquired HIV, between 17-25 years at the time of interview and currently in an intimate relationship, or had been in at least one intimate relationship previously. An intimate relationship was defined as the romantic and/or sexual relationship a person would have with a ‘boyfriend’ or ‘girlfriend’ (either regular or casual). Participants needed to have been fully disclosed to about their HIV by age 16, including the ’naming' of their diagnosis.

The sample comprised seven people with PAH, aged 18-23 years. Demographic and clinical characteristics are presented in Table 1.

**TABLE 1 HERE**

**Ethics and procedure**

Ethical approval was obtained from NHS and University committees. Clinicians identified clients who met inclusion criteria and introduced the study to them. If clients were willing to be seen by the first author (CG) they were led through the study information sheet and consent form (by CG).After informed consent was obtained, participants were interviewed using a semi-structured interview guide (generated in collaboration with the Children’s HIV Association (CHIVA) youth committee). Interviews were conducted in clinic by CG, taking between 50 and 90 minutes, recorded using a digital recorder and transcribed verbatim (by CG).

**Analysis**

Data was analysed using Interpretative Phenomenological Analysis (IPA)([Smith, Flowers, & Larkin, 2009](#_ENREF_19)). For each transcript, initial coding was followed by descriptive/phenomenological and interpretative analysis. These observations were then transformed into emerging themes. In addition to this idiographic focus, individual themes were examined together to establish conceptual links and develop a set of master/subordinate themes. For this article, a subset of the full range of themes from a larger study is presented, those that relate to how HIV disclosure was managed within intimate relationships. Pseudonyms are used throughout.

**Quality**

Quality standards ([Elliott, Fischer, & Rennie, 1999](#_ENREF_9)) were adopted. The sample was situated (through providing demographic and clinical data), the analysis was grounded in examples, credibility checks of the first author’s coding were used (by the second author, ME) and reflexivity was maintained (using a reflective journal).

**RESULTS**

Participants used a range of strategies within intimate relationships to manage HIV disclosure. Often strategies served to either avoid HIV disclosure completely, or to minimise the risk of rejection if disclosure took place. Four themes were elicited.

**Decisions about starting, continuing or resuming relationships shaped by disclosure**

Five of the 7 participants were currently not in regular relationships. Although the absence of regular partners was not always explained in relation to HIV disclosure, sometimes participants admitted that anticipating rejection affected relationship decisions:

*...maybe that’s why I don’t think about having a proper relationship, cos it’s always in the back of my mind sometimes, I think I’m going to tell a girl the situation, she won’t be interested anymore (Benjamin).*

Other participants reported avoiding sex within intimate relationships for fear of revealing their status:

*...if I was gonna have a sexual relationship, soon in time this [peg tube] would get exposed and then I’d have to explain why I’ve got it in... (Helen)*

Renewing relationships with ex-partners, rather than finding new partners, was acknowledged as preferable by three participants. This approach removed the need to face further difficult onward disclosure:

*If anything, I’d prefer to get back with my daughter’s father [laughs], and I*

*think it would be the easiest route out... (Helen)*

*But I don’t know if I didn’t want to end it because of the fact that he’s the*

*first person that I ever told and I felt like I had a special connection with*

*him because of that? (Emily)*

*Then he was like ‘It’s ok, it doesn’t matter’ and he’s stuck by me since. I’m*

*not saying he’s the best person in the world, cos he has been a bastard at*

*certain times during our relationship, but in that situation, he’s fine.*

*(Joanna)*

The above extracts reflected the emotional bond that could arise from having shared one’s status, also commented upon by the following participant:

*Obviously, you feel relieved, it’s cool...you’ve got that trust, you know. (Maxwell)*

**Disclosing early to avoid the pain of future rejection**

The fear of rejection appeared to influence the timing of HIV disclosure for some participants. Two participants expressed a preference for disclosing to partners early, before emotional attachments were formed.

*I wouldn’t want to have sex with somebody and not let them know about my status [ok] because I would feel that they didn’t even have the opportunity to say they didn’t want... (Rebecca)*

A third participant was considering this approach, despite not yet feeling confident enough to disclose:

*And cos I think that there is something about him, I don’t want to, like, wait*

*until later on when I end up getting deep into it and he ends up getting deep*

*into it and then telling him and him being like ‘Well, no, I don’t want to deal*

*with anyone who has HIV’ or whatever, so I’d rather know now. (Charlotte)*

One participant chose to raise early HIV disclosure hypothetically, resulting in their partner also showing a preference for being told early:

*...he said that he wouldn’t want to have that person know that they had*

*something wrong with them, like HIV or whatever, and then get into a*

*relationship with him and then have this deep, dark secret at the back of*

*their mind and not express to him... (Charlotte)*

**Using condoms to avoid disclosure**

Using condoms was regarded as a method of avoiding or postponing the need for onward disclosure, and therefore avoiding feared rejection, by five participants:

*As long as I use protection then I’m fine. So I just made sure that I did that. So yeah, there was no reason for me to tell her. (Benjamin)*

This strategy was not fool-proof and could break down if partners suggested that the couple cease using condoms. This had happened to four participants, with subsequent feelings of pressure and anxiety:

*It was scary, cos, erm, like I moaned, I complained. He was saying ‘what’s there to worry about, like, we’re in love’ and all this….’ (Helen)*

For some, their partner’s desire to stop using condoms was a catalyst for disclosure:

*I think that was the time that he said that he wanted to stop using them. So I thought ‘Right, if that’s the case, I need to tell you now ’. (Charlotte)*

Other participants found that condom use served to divert attention from their own health to their partner’s sexual health:

*Aah, probably make up some excuse or something, like ‘what if you’ve got a disease’ [laughs]. That’s hard, that’s kind of harsh but, yeah, probably make up something like ‘there’s plenty of things going about and obviously we need to use protection and I really can’t do it unless...’. (Benjamin)*

**Testing likely partner reactions to disclosure**

A common strategy was to test their partners’ knowledge of and attitude towards HIV before disclosure, to determine their partner’s likely response and form a judgement concerning the possible risk of rejection in a ‘safe’ way. Three participants asked their partners questions about HIV:

*I, kind of, do this thing where I test the waters first [ok]. So, say for example, I will, like, let’s say if I was to meet someone and we were dating or whatever, I would [laughs] put it like ‘Oh yeah, I work with children with HIV’ and see what their response is and see if they are either like ‘Urgh, HIV’ or ‘Ok, so how do you do that?’... (Charlotte)*

*Like, oh, medical questions [laughs] like ‘Do you know about HIV?’. (Rebecca)*

These participants would then propose hypothetical situations about being in a relationship with an HIV-positive individual:

*I just want to hear what people say…..so I asked my friend ‘Say you had a friend with HIV, what you gonna do, what would you do?’ Well obviously some are like ‘Urgh, no, nah I can’t have that like, no’. (Benjamin)*

If encountering a negative response, these participants would either not disclose their HIV status or would end the relationship:

*I used that with someone else and they, kind of, gave me, it wasn’t a negative response, it was more of ‘Urgh, no’, kind of thing. I was like ‘What do you mean, urgh no?’ and he was like ‘No, I wouldn’t do that’ and I was like ‘Ok, fine. Fair enough’. But then obviously, he didn’t realise or know why I was asking. So I just thought ‘That’s it. No more seeing you’. (Charlotte)*

Although some participants based their decisions on the responses given by their partners, others were aware partner responses could only ever be hypothetical.

*As you can tell someone, you can ask someone the questions, they might have this whole idea of ‘Oh yeah, I’d stick by you’, they might....really want to, but then deep down, when it really comes down to it, when you’re faced with the actual situation, you may flee. So I was thinking to myself ‘Alright, he’s reacted in a positive way now and that’s fine, that’s all good but, if I was to actually tell him that it’s me, that has HIV, how would he react to it?’. (Charlotte)*

**DISCUSSION**

Participants used various strategies to minimise the pain of rejection by partners associated with HIV disclosure. These involved (1) Decisions about starting, continuing or resuming relationships shaped by disclosure (2) Disclosing early to avoid the pain of future rejection (3) Using condoms to avoid disclosure (4) Testing likely partner reactions to disclosure.

Decisions about whether to be in relationships, who to be in relationships with and sexual behaviour within relationships were shaped by disclosure concerns. Self-protective motivations appeared to constrain relationship choices with a tendency to either settle for being single or for relationships that were somewhat unsatisfactory but where, at least, one’s HIV status had been ‘accepted’. The tendency to avoid penetrative sex (in this study, linked to disclosure avoidance) in youth with PHIV has been reported in other populations ([Bauermeister, Elkington, Brackis-Cott, Dolezal, & Mellins, 2009](#_ENREF_2)). Relationship choices, shaped by disclosure concerns, may have protected individuals’ well-being, at least in the initial stages of their relationship history. It is unclear if the same level of influence of HIV disclosure on relationships would be seen in older individuals with PAH or whether the impact continues to be appraised adaptively over longer periods.

The decision by some participants to disclose early to avoid greater anticipated pain of rejection was another example of how disclosure shaped relationship decisions. Despite this appearing to be an active strategy reflecting a desire to take control of relationship outcomes (and minimise risk of onward transmission) it could be interpreted as a form of avoidance. Cognitive models of anxiety would describe such a strategy as a ‘safety behaviour’ – a behaviour designed to avoid exposure to a feared outcome, in this case the greater anticipated pain of rejection if one were to wait for mutual feelings to deepen before disclosure took place. It is unclear whether a strategy of early disclosure is beneficial or counterproductive to individual wellbeing.

Condoms were used to avoid disclosure. Condoms may also have been used to reduce onward transmission risk, minimise potential legal consequences and due to feelings of interpersonal responsibility, factors reported by youth with PAH in other studies ([Fernet et al., 2007](#_ENREF_13)). Disclosure to partners can itself be effective in reducing sexual risk behaviour in HIV positive populations (due to decisions to avoid/reduce the frequency of intercourse or only engage in low risk activities, and also due to increased condom use if intercourse takes place) ([Pinkerton & Galletly, 2007](#_ENREF_18)). Choosing to use condoms as a way to avoid disclosure left individuals unprepared for times when partners asked to have unprotected sex. This situation arose frequently and was very anxiety-provoking.

A common strategy was to test attitudes of partners through asking questions and proposing hypothetical situations. Participants used their partners’ responses to form judgements about the likely risk of rejection and to make decisions about disclosure and/or relationship continuation. This seemed to afford individuals a sense of control and predictability regarding disclosure outcomes, although some participants also considered that partners might react differently in reality. Similar testing of the hypothetical response

of partners to HIV disclosure has been reported in behaviourally infected young women (aged 18 to 24 years) in the US ([Clum et al., 2013](#_ENREF_7)).

Overall, both HIV disclosure-related rejection fears and the range of ways that HIV disclosure was managed within relationships were consistent with reports from behaviourally infected HIV-positive populations in resource rich contexts ([Clum et al., 2013](#_ENREF_7); [Derlega, Winstead, Greene, Serovich, & Elwood, 2004](#_ENREF_8)). There was little that participants reported about how they managed disclosure that they explicitly related to having grown up with HIV. The extent to which HIV is often a ‘secret’ within families of individuals with PAH (with direct advice not to share one’s status), may make onward disclosure in relationships even more difficult in this population. This was not acknowledged or reflected upon in our sample, however.

It is also of note that many of the themes from our participants (of sub-Saharan African origins) have also been reported in younger sub-Saharan African cohorts. For example, concerns about partner responses to disclosure have been reported in Rwandan HIV positive adolescents (median age 17 years) ([Van Nuil et al., 2014](#_ENREF_21)) and HIV disclosure concerns have been noted in perinatally infected Tanzanian adolescents ([Busza, Besana, Mapunda, & Oliveras, 2013](#_ENREF_4)) (aged 15 to 19 years). The latter participants anticipated postponing or avoiding sex indefinitely. It will be important to assess if such perinatally infected sub-Saharan African cohorts report similar themes as they enter young adulthood.

The small sample size, few male participants and non-representative sampling strategy are all study limitations. Focussing on older participants than most previous study samples, however, allowed for richer accounts of relationships. The sample was somewhat homogeneous in age, ethnic background and age at full disclosure/naming, as recommended in IPA studies ([Smith et al., 2009](#_ENREF_19)). A number of procedures were used to increase the results’ validity and reliability ([Elliott et al., 1999](#_ENREF_9)).

Given the importance of limiting onward HIV transmission, it is surprising that there are no sexual risk reduction interventions specifically for young people with PAH. Our study shows that decisions about sharing one’s status are closely tied with relationships and sexual behaviour decisions in this population. As such, it is also surprising that no interventions have been developed to support onward disclosure in young people with PAH, despite calls ([Evangeli & Foster, 2014](#_ENREF_10)). These interventions could focus on examining personal motivations for HIV disclosure, using approaches such as motivational interviewing and cognitive behavioural therapy. Interventions could also aim to develop young peoples’ skills in disclosure communication, goal setting and planning, using role play and modelling techniques. Guidance is also required for professionals to assist their clients, particularly given recent evidence that professionals do not frequently discuss disclosure with young adults with PAH ([Albright & Fair, 2014](#_ENREF_1)).

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**Table 1 – Participant demographic and clinical characteristics**

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| --- | --- | --- | --- | --- | --- | --- | --- |
| Participant (pseudonym) | Sex | Age | Ethnicity | Age at naming/full  disclosure | CD4  Count(mm3) | Viral Load | ART |
| Rebecca | F | 18 | Black African | 15 | 50 | 25354 | No |
| Helen | F | 23 | Black African | 12 | 40 | 108 | Yes |
| Benjamin | M | 20 | Black African | 15 | 420 | <50 | Yes |
| Charlotte | F | 21 | Black African | 12 | 400 | <50 | Yes |
| Emily | F | 23 | Black African | 13 | 320 | <50 | Yes |
| Joanna | F | 22 | White  British | 16 | 40 | 187626 | Yes |
| Maxwell | M | 23 | Black  African | 14 | 720 | 72 | Yes |

1. Department of Clinical Psychology, Royal Holloway, University of London, Egham Hill, Egham, Surrey, TW20 0EX [↑](#footnote-ref-1)
2. [↑](#footnote-ref-2)
3. 2 The 900 Clinic, Imperial College Healthcare NHS Trust, St. Mary’s Hospital, Praed Street, London, W2 1NY

   Correspondence: Dr. Michael Evangeli. [michael.evangeli@rhul.ac.uk](mailto:michael.evangeli@rhul.ac.uk) [↑](#footnote-ref-3)
4. [↑](#footnote-ref-4)
5. [↑](#footnote-ref-5)