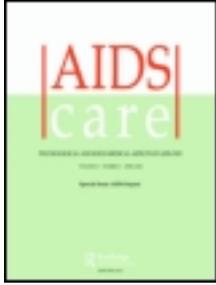


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## Intimate relationships in young adults with perinatally acquired HIV: Partner considerations

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Due to developments in anti-retroviral treatment, an increasing number of children with perinatally acquired HIV are now surviving into late adolescence and young adulthood. This cohort is facing normative challenges in terms of their intimate relationships as well as challenges that face all individuals with HIV regardless of the route of transmission (for example, concerns about disclosure). There may be additional issues specific to having grown up with HIV that affect intimate relationships, for example, the awareness of being HIV positive before the onset of intimate relationships and the way that identity is shaped by having lived with HIV from a young age. To date there has been some limited research on the experience of intimate relationships in perinatally infected adolescents but none in young adults. This exploratory study examined, in depth, experiences of intimate relationships in perinatally acquired young adults and how they perceived having grown up with HIV to have affected such relationships. Seven participants (five females, two males) aged 18–23 years, were interviewed, with the data analysed according to the principles of interpretative phenomenological analysis (IPA). Three themes emerged that related to partners' perceptions of HIV: (1) HIV being viewed by partners as being linked to AIDS and sexual transmission, (2) discrepancy between young people and their partners' views of HIV, (3) partner views of risk of HIV transmission. There were strong links between participants' personal experiences of HIV-related challenges, for example, disclosure and HIV-related stigma, and their thinking about the perceptions of partners. These findings have important implications for supporting young people in disclosing their HIV status to intimate partners in appropriate ways. Suggestions for future research are offered.

**Keywords:** HIV; perinatal infection; young adults; relationships; partners; IPA

### Introduction

Antenatal HIV-testing and interventions to reduce mother-to-child transmission have led to marked reductions in perinatal HIV transmission in high income countries (Center for Disease Control and Prevention, 2005). Individuals with perinatally acquired HIV in the UK are, therefore, mostly adolescents and young adults, with 70% over the age of 10 (Collaborative HIV Paediatric Study, 2011). As a consequence, intimate relationships are a central concern of this cohort.

The relationship stressors faced by perinatally infected young people include (1) normative developmental challenges (Wiener, Mellins, Marhefka, & Battles, 2007), (2) challenges experienced by HIV-positive individuals irrespective of transmission route and (3) those related specifically to perinatal transmission. Regarding the latter, considerations about disclosure of one's HIV status and an identity shaped by having lived with HIV throughout childhood may affect first intimate relationships, in contrast to horizontally infected individuals.

Some studies have examined experiences of intimate relationships in adolescents with perinatally acquired HIV infection, using qualitative methodologies

(e.g., Fernet et al., 2007; Fielden et al., 2006). Themes elicited included strong concern about the potential impact of disclosure on the continuation of relationships. The present study aimed to (1) focus on how perinatally infected participants felt that growing up with HIV impacted on intimate relationships, (2) describe the experience of intimate relationships in an older cohort than previously studied.

### Method

#### *Design and sampling*

The study used a qualitative cross-sectional design. Sampling was purposive, with attempts to recruit young people who were identified by clinicians as likely to agree to participate.

#### *Setting*

Recruitment from an NHS clinic in London where approximately 65 perinatally infected patients aged 16–25 years are seen for their HIV management by a multi-disciplinary team.

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Table 1. Demographic characteristics of participants

Participant <sup>a</sup>	Gender	Age	Ethnicity	Age at disclosure	CD4 count	Viral load	Prescription of anti-retroviral medication
Rebecca	F	18	Black African	15	50	25,354	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	187,626	Yes
Maxwell	M	23	Black African	14	720	72	Yes

<sup>a</sup>Pseudonyms allocated to participants.

## Participants

### Sample

The sample comprised seven young people with perinatally acquired HIV, aged 18–23 years (demographic characteristics in Table 1).

Participants were currently in an intimate relationship, or had been in at least one regular or casual intimate relationship previously, and had their HIV status disclosed to them by the age of 16. Individuals were excluded if the clinical team considered that involvement would be likely to have an adverse impact on their emotional health or engagement with services.

### Procedure

Ethical approval was obtained by the relevant NHS and University committees. After consent was obtained, participants were interviewed by the first author about their experiences intimate relationships with a semi-structured interview that was developed in collaboration with the service users from the UK Children's HIV Association (CHIVA) youth committee. Interviews took place in the participants' regular clinic.

### Analysis

The data was analysed using interpretative phenomenological analysis (IPA; Smith, Flowers, & Larkin, 2009). Codings and themes were initially developed by the first author and verified by the second author. For the purposes of this article, a subset of the full range of themes is presented.

## Results

### *HIV viewed by partners as linked to AIDS and sexual transmission*

There appeared to be a link between participants' response to finding out about their own HIV status

and concerns about how their partners would respond to disclosure of their status. For the majority of participants, six of whom were of Black African ethnicity, HIV in Africa was their main frame of reference when they were disclosed to regarding their HIV status. This led to an association with AIDS and a marked fear of death until they obtained further information:

I'd always heard about HIV in Africa...and I thought 'Oh my god, I'm going to die' so then I broke down and started crying... (Charlotte)

There was a concern that some partners, on being disclosed to, would have similar thoughts about prognosis and would also become extremely anxious about the risk of contracting the virus themselves. Some participants would provide information to contain their partner's anxiety:

Like now, if someone finds out about HIV they're like 'Oh, AIDS' and I'm like 'No. There's a difference'. (Charlotte)

Concern was also expressed that HIV would be associated solely with sexually transmission in partners' minds. Two participants were worried that, if this were the case, partners might unjustly question their fidelity and assume that they had been unfaithful or promiscuous:

obviously some people don't have knowledge that they can be born with it or can get it from blood transfusions [...] it wouldn't have all added up ... (Helen)

The lack of understanding about perinatal transmission was considered to be influenced by how HIV had been presented, for example, in school settings. Participants drew on their own experiences of learning about HIV when considering the potential views of their partners:

...it would be in sexual health [right] so they are basically telling children that the only way you can contract HIV is from sex and it's not, cos I didn't get it through sex, I got it through birth. (Charlotte)

### ***Discrepancy between young people and their partners; views of HIV***

Three participants described having experienced a marked contrast between their own view of HIV as manageable, and those of their partners:

I ask them like 'say you had HIV, well what are you gonna do?' and they usually say 'I'd think my life's over' ... and I'm thinking, 'you don't know about it'. (Benjamin)

Four participants said that the way that HIV was presented to partners and whether their anxiety could be contained was considered to highly influence how partners would react. For one, this viewpoint was formed through her own experience of having been disclosed to where she had not felt reassured:

if I'm like 'Argh, I'm so sorry' [i.e., when disclosing HIV] they're going to be like 'Oh my gosh'. (Emily)

### ***Partner view of risk of HIV transmission***

When participants had disclosed to partners, some partners became very committed to the use of condoms, whereas others dealt with the risk of transmission passively:

...even after I told him before he got his bloods and he didn't know whether he was positive or negative, he still wanted to continue. I was like, I was like 'there's a good chance that you might not have it' and he was like 'oh if I've got it, I've got it - if I don't, I don't'. (Helen)

An important dilemma appeared to be how the seriousness of HIV could be communicated to partners in such a way that they would be encouraged to take the virus seriously and manage risk, but without the partner becoming so anxious that they would end the relationship. Sometimes, attempts to reassure partners appeared to lead to reluctance to take appropriate health steps:

I basically started to explain to him bit by bit how it is and how it's not the end of the world and then he didn't want to go clinic... (Helen)

This dilemma was often reflective of their own HIV disclosure experiences, with caregivers and clinicians reportedly balancing an emphasis on the serious

nature of HIV, such as the need for consistency with medication, with a sense of hope for the future:

It's like they're trying to make the seriousness of it but, you know, that the disease was liveable. (Emily)

### **Discussion**

Participants described their anxieties regarding the attitudes that partners may hold regarding HIV. Three themes emerged: (1) HIV as linked to AIDS and sexual transmission, (2) a discrepancy between young people and their partners' views of HIV, (3) partner views of risk of HIV transmission.

The fear of the association between HIV and AIDS/death appeared to mirror participants' own experiences of learning about HIV. There may also have been an association between participants' ethnic background and the frame of reference used to perceive the condition. The concern that partners would consider unprotected sexual behaviour to be the sole route of transmission has been reported previously in this population (Wiener, Battles, & Wood, 2007).

There appeared to be a concern that partners would over-inflate the risk of transmission and the risk of death and thus find it too difficult to be in an HIV-affected relationship. To manage this, some attempted to educate their partners but there were difficulties in balancing the containment of their partners' anxieties with encouraging them to continue to take HIV seriously.

This exploratory research studied an older group of individuals with perinatally acquired HIV, with more detailed relationship histories, than has been reported to date. Care was taken to enhance the validity of the analysis (e.g., Elliott, Fischer, & Rennie, 1999) although respondent validation would have been useful. The applicability of findings beyond the sample population may be limited, however, given the purposive nature of the sampling strategy and the small sample.

The results suggest that ongoing attempts should be made by clinicians to advise (and model) disclosing one's HIV status to partners in a way that is balanced and accurate. An interesting area of future qualitative research would be to interview young people with perinatally acquired HIV and their partners to explore the experience of being in an HIV-affected relationship. This design would aid considerations of the type of support that is best to provide. In addition, larger studies with more representative sampling strategies would be an important further step.

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