

Parenting considerations in young adults with perinatally-acquired HIV

RESEARCH ARTICLE

**Michael Evangelì¹, Clare Greenhalgh¹, Graham Frize²,
Caroline Foster², Sarah Fidler²**

¹ Department of Clinical Psychology, Royal Holloway University of London, Egham Hill, Egham, Surrey, TW20 0EX, UK

² The 900 Clinic, Imperial College Healthcare NHS Trust, London, W2 1NY.

Correspondence:

Dr Michael Evangelì, Department of Clinical Psychology, Royal Holloway University of London, Egham Hill, Egham, Surrey, TW20 0EX, UK.

Email: michael.evangelì@rhul.ac.uk

Abstract

An increasing number of children born with perinatally-acquired HIV (PAH) are surviving into late adolescence and early adulthood. At this developmental stage, developing intimate relationships and having children are potentially important goals with associated normative challenges. Young people with PAH face a variety of additional *HIV-related* stressors that may be associated with relationships and parenting. These may include managing HIV disclosure to their partner, and adherence to antiretroviral medication to (a) prevent transmission to partners and future offspring and (b) maintain their own health. Some of these challenges may be impacted upon by issues associated with having been born with HIV, for example, managing longstanding secrecy about HIV, and having been told from a young age that life expectancy could be shortened. To date, there has been limited research into the procreational and parenting reflections of young people with PAH. This study examined the hopes and concerns that a group of young people with PAH have regarding having children. Seven participants (five females, two males) currently or previously in an intimate relationship, aged 18-23 years, two of whom were parents, were recruited from a UK hospital clinic. They were interviewed using a semi-structured interview, with data analysed according to the principles of Interpretative Phenomenological Analysis (IPA). Four main themes were elicited: the perceived impact of having a child on intimate relationships, the effect of normative beliefs on parenting intentions and expectations, thoughts and feelings about disclosing parental HIV status to one's children in the future, and the perceived impact of HIV on procreational intentions. Implications for supporting young people with PAH in parenting decision-making are explored.

Key words: HIV, perinatally acquired, procreational intentions, parenting intentions, young adults

Introduction

Individuals with perinatally acquired HIV (PAH) in the UK are mostly adolescents and young adults (Collaborative HIV Paediatric Study, 2011) with some thinking about having or having had children. Pregnancy rates in cohorts with PAH may be lower than in uninfected peers in resource rich contexts (Brogly et al, 2007; Kenny, Williams, Prime, Tookey & Foster, 2012). Kenny et al (2012) reported that 34/42 (81%) pregnancies in a UK cohort were unplanned and in 21/42 (50%) of pregnancies the partner without PAH was unaware of their partner's HIV status.

High rates of procreational *intentions* in those with PAH have been reported in US adolescents and young adults (e.g., Fair & Albright, 2012). Across different contexts, higher parenting intentions rates in this population are associated with: perceived low risk of mother-to-child transmission (Ezeanolue, Wodi, Patel, Dieudonne, & Oleske, 2006), perceived HIV treatment advances (Cliffe, Townsend, Cortina-Borja, & Newell, 2011), recent intercourse, unprotected sex and lower HIV disclosure rates (Finger et al, 2012), being in a seroconcordant couple (Bonnenfant, Hindin & Gillespie, 2012), the perception of partner procreational desire (e.g., De la Cruz, Davies, & Stewart, 2011), and being childless (Rispel, Metcalf, Moody, Cloete, & Caswell, 2011).

Feelings and thoughts about parenting, other than parenting intentions, have received little attention. How cultural beliefs or the experience of growing up with HIV are related to parenting has not been studied. We used an in-depth qualitative approach to examine parenting experiences, hopes and concerns in young people with PAH.

Methods

Design and setting

We used a qualitative cross sectional design. Participants were recruited from a multidisciplinary London NHS clinic for 16 to 25 year-olds, with a caseload of 65 individuals with PAH.

Participants

Sample

Seven people with PAH, with a current or past intimate partner, aged 18-23 years, were recruited (Table 1) (out of 12 approached). None in a current relationship had an HIV positive partner. All participants had had their HIV status fully disclosed to them by aged 16.

TABLE 1 HERE

Procedure and interview protocol

Ethical approval was obtained from University and NHS committees. After consenting, participants were interviewed using a semi-structured interview.

Analysis

Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009) was used.

Codings were developed by the second and verified by the first author.

Results

Two participants, Helen and Joanna (all names are pseudonyms) were parents. The other five wanted to have children. Four themes were elicited:

Impact of children on intimate relationships

The perceived impact of having children on relationships was commonly discussed. Both mothers believed that having children had put pressure on their relationships:

I got pregnant and we started falling out, during the pregnancy. A lot....we broke up when I was...five months pregnant. (Helen)

Both were concerned about the HIV transmission risk to their babies during pregnancy. One had concerns that her partner (whom she had not disclosed to) would abandon her and the baby, if mother-to-child transmission occurred:

I was scared that if I did tell him and she did have it.....he might go....for good, desert both of us.....and want nothing to do with me for not telling him. (Helen)

Some participants without children feared that starting a family would affect future relationships:

.....they might turn around and say 'Well, I can't do this any longer, I can't have kids with you'...(Charlotte)

Impact of culture, family and social norms on parenting intentions and expectations

Normative familial, cultural or societal beliefs were important when thinking about parenting for six participants (all self-defined as Black African). For example, African cultural values, including those of obedience, respect and the importance of marriage, were mentioned:

My dad's quite strict so I don't want to be that kind of (parent), but I understand why he's like that, his background, African.. (Benjamin)

Respect [in my culture] is a major thing... my kids will respect me.....they will have to. (Charlotte)

Some participants anticipated less future HIV stigma, making their child's adjustment easier than theirs:

I think it'll be..... more open and not as much of a taboo when I have my kids. Even if they don't have it, I don't want them to go into school and the teachers are teaching about HIV in a negative way..... well my generation didn't get the whole 'HIV- it's not that bad', it was just 'HIV – scary' (Charlotte).

Disclosure of HIV to children

Four participants reflected on disclose to their children about their HIV status. Some compared their own HIV disclosure experience to how they hoped to disclose to their children:

Before, whenever I spoke to my mum about it...she was upset about it and it got me

upset so I didn't....open up. I'd try to contain myself [with my own children] and be like 'Alright, it's not that bad' cos if I make out that it's nothing, it's normal, then they'll be like 'Oh, so Mummy's fine, she doesn't think nothing of it' and then it's alright (Charlotte)

I had a really good doctor...he was like a big uncle or big brother.. [he would] tell me [it] was alright....I would do something similar, I would get someone that my children are comfortable with, let's say their father or their uncle.... I'd bring them in and explain it to them. (Charlotte).

Impact of HIV on procreational intention

Two participants reported that HIV impacted upon their procreational intentions. Having an HIV-related illness was perceived by one mother as affecting the likelihood of having another child:

I have thought about it, cos sometimes I get broody.....but at the moment with my CD4 being very low and my viral load being very high there's not a chance (Helen)

One participant was concerned about HIV transmission to a child:

Yeah, [I worry about] giving them HIV... if they did have HIV, the pressure or the stigma of it... feeling like it's the end of the world (Rebecca).

Discussion

We examined parenting issues in young adults with PAH. High rates of parenting intentions were reported (as in Ezeanolue et al, 2006). Some parenting issues were directly HIV-related (e.g., disclosure to one's child) whilst others were not (e.g., normative beliefs about how to parent). Few issues were directly related to the *perinatal* route of HIV acquisition. HIV communication in the past, however, was thought about in relation to child HIV disclosure. Participants also discussed how normative beliefs when growing up with HIV impacted upon parenting issues. For some, there was a desire to parent differently to the way that they were parented. There was also hope that societal HIV views would change so that their children would be less affected by stigma.

Some participants' HIV-related health impacted upon their procreational intentions. Generally, however, the sample wanted to become parents regardless of (1) their health (2) having had HIV transmitted from birth (3) growing up with HIV. The relationship between the sample's predominantly Black African ethnicity and high levels of parenting intentions are consistent with associations between ethnicity and pregnancy in UK HIV positive women (Huntington et al, 2012).

Experiences and concerns about the effect of having children on relationship were common and appeared to relate to partner responses to HIV disclosure. Such anxieties may be rational given high rates of partnership dissolution following HIV diagnoses in serodiscordant couples (Reniers & Armbruster, 2012). It is unclear whether (1) concerns about partner responses may be associated with high rates of unplanned pregnancies and limited partner HIV disclosure (Kenny et al, 2012) (2) observations of the effects of HIV on one's parents relationships may have influenced participants' views.

Our findings may be relevant to resource limited contexts, given participants' predominantly Black African ethnicity and the importance of family and cultural norms. There may be different levels of procreational intentions in HIV positive populations in different contexts, however (e.g., Kaida et al, 2011). The relationship between parenting intentions and subsequent childbearing is also unclear, regardless of location.

Participants were similar in age, ethnicity, ART use, age at disclosure and relationship history (as recommended in IPA: Smith et al, 2009). The views of both sexes, those with and without children, and with a range of CD4 counts, were elicited. Steps were taken to enhance study validity and reliability (e.g., credibility checks: Elliott, Fischer, & Rennie, 1999). The sample size limits generalizability. IPA, however, justifies small samples due the level of detailed idiographic analysis. Also, sample homogeneity restricts the range of possible themes elicited, allowing for smaller samples (Smith et al, 2009).

Our findings suggests that young people with PAH wish to have children and are thinking about parenting issues, for example, HIV partner and child disclosure. As suggested by others parenting intentions should be assessed, and we suggest that broader parenting considerations are also explored. Strategies to help people with PAH communicate with their partners about HIV should be discussed and open communication about parenthood and HIV should be facilitated in individual, couple or group sessions. Finally, it may be that parenting intentions are formed at a younger age and, therefore, exploring parenting considerations in paediatric settings could also be important.

References

Bonnenfant, Y. T., Hindin, M.J., & Gillespie, D. (2012). HIV diagnosis and fertility intentions among couple VCT clients in Ethiopia. *AIDS Care*, 24(11), 1407-15.

Brogly, S. B., Watts, D. H., Ylitalo, N., Franco, E. L., Seage, G. R., Oleske, J., et al. (2007). Reproductive health of adolescent girls perinatally acquired with HIV. *American Journal of Public Health*, 97(6), 1047-1052.

Cliffe, S., Townsend, C. L., Cortina-Borja, M., & Newell, M. L. (2011). Fertility intentions of HIV-acquired women in the United Kingdom. *AIDS Care*, 23(9), 1093-1101.

Collaborative HIV Paediatric Study (CHIPS) (2011). *Annual Report 2010/11*. CHIPS.

De la Cruz, N. G., Davies, S. L., & Stewart, K. E. (2011). Religion, Relationships and Reproduction: Correlates of Desire for a Child Among Mothers Living with HIV. *Aids and Behavior*, 15(6), 1233-1242.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.

Ezeanolue, E. E., Wodi, A. P., Patel, R., Dieudonne, A., & Oleske, J. M. (2006). Sexual behaviors and procreational intentions of adolescents and young adults with perinatally acquired human immunodeficiency virus infection: experience of an urban tertiary center. *Journal of Adolescent Health*, 38(6), 719-725.

Fair, C., & Albright, J. (2012). "I've always wanted a child": Fertility desires/intentions and knowledge of mother to child transmission among individuals with perinatal-acquired HIV. *American Public Health Association Conference*, San Francisco, US, October 2012.

Finger, J. L., Clum, G.A., Trent, M.E., Ellen, J.M., & the Adolescent Medicine Trials Network for HIV/AIDS Interventions. (2012). Desire for Pregnancy and Risk Behavior in Young HIV-Positive Women. *Aids Patient Care and STDs*, 26(3), 173-180.

Huntington, S., Thorne, C., Anderson, J., Newell, M-L., Taylor, G., Pilaay, D., Hill, T., Tookey, P., & Sabin, C. (2012). Pregnancies among women seen for HIV-clinical care - predictors and trends over time. *HIV Medicine*, 13(Supplement1), 35-36.

Kaida, A., Laher, F., Strathdee, S. A., Janssen, P. A., Money, D., Hogg, R. S., et al. (2011). Childbearing Intentions of HIV-Positive Women of Reproductive Age in Soweto, South Africa: The Influence of Expanding Access to HAART in an HIV Hyperendemic Setting. *American Journal of Public Health*, 101(2), 350-358.

Kenny, J., Williams, B., Prime, K., Tookey, P., & Foster, C. (2012). Pregnancy outcomes in adolescents in the UK and Ireland growing up with HIV. *HIV Medicine*, 13(5), 304-8.

Reniers, G., & Armbruster, B. (2012). HIV status awareness, partnership dissolution and HIV transmission in generalized epidemics. *PLoS One*, 7(12), e50669.

Rispel, L. C., Metcalf, C. A., Moody, K., Cloete, A., & Caswell, G. (2011). Sexual relations and childbearing decisions of HIV-discordant couples: an exploratory study in South Africa

and Tanzania. *Reproductive Health Matters*, 19(37), 184-193.

Smith, J. A., Flowers, P., & Larkin, M. . (2009). *Intepretative Phenomenological Analysis*:
London:Sage.

Table 1 – Demographic characteristics of participants

Participant	Gender	Age	Ethnicity	Age at disclosure	CD4 count	ART
Rebecca	F	18	Black African	15	50	No
Helen	F	23	Black African	12	40	Yes
Benjamin	M	20	Black African	15	420	Yes
Charlotte	F	21	Black African	12	400	Yes
Emily	F	23	Black African	13	320	Yes
Joanna	F	22	White British	16	40	Yes
Maxwell	M	23	Black African	14	720	Yes